

Back to School, Back to Normal? Exploring the Lived Experiences of Childhood Cancer
Survivors and their Families Throughout the School Re-Entry Process

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Abstract

This study investigated parent and child perspectives of childhood cancer survivors' return to school. Four specific areas were examined including cognitive and academic concerns, social issues, perceived support, and the impact on siblings. Participants consisted of parents and childhood cancer survivors who were recruited through a regional parent support group. Data was collected during a focus group and interviews. Using a descriptive content analysis, results indicated that participants generally received the necessary resources, however issues such as consistency and having to advocate in order to attain these resources served as barriers for the families.

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Love, Marlene

Table of Contents

Abstract.....	ii
Table of Contents	iv
List of Tables	viii
List of Figures.....	ix
Introduction	1
Literature Review	3
Childhood Cancer	3
Medical Issues Relating to School Re-Entry	5
The Importance of School Re-Entry	6
Facilitating School Re-Entry	7
Peers and Social Relationships.....	10
Social Inclusion	13
Cognitive and Academic Effects of Childhood Cancer	14
Special Education in Ontario	19
Teachers.....	22
Parents' Experiences of School Re-Entry	24
Siblings' Experiences.....	26
Rationale and Research Question	32
The Researcher's Role	34
Method.....	36
Data Collection Procedures	36

Participants	37
Participant selection and recruitment	38
Focus group.....	40
Interviews.....	42
Parent interviews.....	42
Childhood cancer survivor interviews.	43
Data Analysis and Interpretation	45
Results	50
Challenges Associated with Cancer (Cognitive, Behavioural, Physical)	51
Not wanting to be different.	52
Physical changes.	53
Cognitive functioning.....	56
Academic issues related to cognitive functioning	57
Resilience and striving to achieve.	60
Behavioural changes and challenges.....	61
Social and Peer Related Aspects of the Cancer Experience.....	62
Nature of peer relationships.....	64
Supportive peer relationships.....	66
Non-supportive peer relationships.....	69
Peer knowledge and education relating to cancer.....	71
Perceived Support.....	73
Infrastructure.....	73
Meetings with school personnel.....	74
Funding and coordinating support	76
Measures taken to obtain support.	78

Identification.....	79
Educational hierarchy.....	81
Hospital teachers.	82
Tutors.....	83
Home instruction.	84
Re-entry programs.....	86
Educating the educators	90
Invisible disability	91
School climate	92
Accommodations and modifications	94
Principals	95
Teachers	97
Non-supportive teachers.....	99
Supportive teachers.....	101
Educational Assistants	102
Additional sources of support	103
Support recommendations for other families	105
Siblings.....	107
Forced change in routine.....	107
Advocacy.....	118
Fighting.....	120
Being Normal	121
Differences in Experiences Between Families	124
Discussion	125
Challenges Associated with Cancer.....	125

Social and Peer Related Aspects of the Cancer Experience	128
Experiences of Others	147
Limitations and Suggestions for Future Research.....	147
Perspectives and testimonies.....	147
Research design.....	150
Summary	152
Conclusion.....	153
References.....	157
Appendix A: Letter of Invitation.....	163
Appendix B: Parent Consent Form	164
Appendix C: Focus Group Questions	168
Appendix D: Parent Interview Questions	170
Appendix E: Childhood Cancer Survivor Interview Questions	172
Appendix F: Sibling Interview Questions.....	174
Appendix G: Child Assent Form	175
Appendix H: Sibling Assent Form.....	177
Appendix I: Demographic Questionnaire	179

List of Tables

Table 1: Focus Group Participants	39
Table 2: Parent Interview Participants	39
Table 3: Childhood Cancer Survivor Interview Participants	39

List of Figures

Figure 1: Data Analysis Model

48

Back to School, Back to Normal? Exploring the Lived Experiences of Childhood Cancer Survivors and their Families Throughout the School Re-Entry Process

Introduction

The past 50 years have been characterized by a dramatic increase in survival rates for childhood cancer (Eiser, 2004; Sullivan, Fulmer & Zigmond, 2001). Although the incredible survival rates are an excellent accomplishment, it is important to understand that with so much attention being paid to the physical and medical aspects of treatment, our knowledge of the social and psychological consequences of childhood cancer is limited (Vance & Eiser, 2002). The increase in survival rates have resulted in issues relating to the physical and psychological effects of the disease to become increasingly important (Lahteenmaki, Huostila, Hinkka & Salmi, 2002) as has the need to understand the life experiences of children with cancer not only during, but also after their recovery (Sullivan et al., 2001).

To date, little has been done to understand and help to minimize the implications that the disease and its treatment have on a child's quality of life. Since in the past, very few children diagnosed with cancer were cured, issues of education and quality of life were overshadowed by the need to focus on medical treatment (Bessell, 2001). The gains associated with these medical advancements have also created problems relating to the reintegration of students with chronic illness back into school settings (Madan-Swain, Fredrick & Wallander, 1999). There is now an emergent trend that stresses the importance of incorporating the provision of comprehensive care for pediatric cancer patients that recognizes the social and emotional needs of the children in addition to their clinical needs (Eiser, 2004). Part of this comprehensive treatment program for children

with illness includes a focus on the continuation of their social and academic development (McCarthy, Williams & Plumer, 1998). The education of children with cancer and those who have survived cancer is a particularly important issue, as school is an institution that is designed to foster the healthy social and psychological development of children. Sullivan and colleagues (2001) highlight the importance of attending school by stating that it, “anchors their lives” (p. 5), as it acts as a primary influence on social as well as academic development. School re-entry is seen as a major component for a child returning to the normal routines of everyday life following diagnosis and treatment (McCarthy et al., 1998; Sullivan et al., 2001). Bessell (2001) furthers this point by suggesting that successful school experiences are important for a child’s sense of normalcy in their life. The return to school following diagnosis and treatment is encouraged in order to allow children opportunities to interact with their peers and substitute the role of a patient with that of a student or child.

The advances in medical treatment and astonishing survival rates have lead to childhood cancer evolving from what was once seen as a fatal illness, to a disease that is now viewed as a life-threatening chronic disease (Bessell, 2001; Eiser, 2004). This change in reference, making cancer a chronic condition that children must live with, indicates why it is important to focus on ways to maintain a relative degree of normalcy in the life of a child who has cancer. Once diagnosed, the lives of children with cancer are immediately changed. As Bessell (2001) indicates, childhood activities such as sleepovers and camping trips are often substituted with hospitalizations and other medical procedures. Children with cancer should have the opportunity to behave and be treated like normal children, and this includes doing things that they would have done normally,

prior to their diagnosis. Attending school and maintaining relationships with peers are a part of this normal functioning. As a result of this push towards normalcy and the return to school, this project has been developed to gain a better understanding of what it is like for a child with cancer to be in school, as well as how their family members experience their return. This will include learning about their views of school, their peer relationships and academic concerns as well as their perceptions of the experience and any other issues that parents and children believe are important in shaping this experience.

Literature Review

Childhood Cancer

Each year in Canada, an estimated 850 children under the age of 14 are diagnosed with cancer (Canadian Cancer Society/National Cancer Institute of Canada, 2008). Between 2003 and 2007, there were approximately 6,550 children and youth between the ages of 0 and 19 who were diagnosed in Canada (Canadian Cancer Society's Steering Committee on Cancer Statistics, 2011). Mortality rates are declining more steadily for children up to age 19 than for any other age group of people with cancer. During the 1950s and 1960s there was an emergence of new treatments for childhood cancer (Eiser, 2004). Since then, survival rates for childhood cancer have been increasing dramatically, and now about 82% of children diagnosed with cancer are cured (Canadian Cancer Society/National Cancer Institute of Canada, 2008; Canadian Cancer Society's Steering Committee on Cancer Statistics, 2011). Although childhood cancers account for only a tiny percentage of all cancers, they are a significant public health issue. Barr and Sala (2003) note that the changes in the health care system, shifting a majority of services to outpatient clinics, result in a significant burden on families as a number of costs are

transferred to them. These costs can be direct expenditures for uninsured care as well as lost income for family members who act as caregivers. Families often experience emotional trauma, and in many cases, are forced to alter their lifestyles in order to accommodate the many challenges that they face. These challenges are ongoing and continue even after treatment has ended. The impact that these challenges place on individual families can affect society as well in that the financial, physical and emotional responsibilities that the disease imposes on the family may result in families requiring resources to provide for other needs, such as food or housing assistance (Barr & Sala, 2003).

As childhood cancer is still a fairly rare disease, there are many misconceptions that lead people to assume that childhood cancer is the same as, or similar to, adult cancers (Keene, 2003). Compared to adult cancers, very little is known about the causes of childhood cancer. While there are a number of studies that have examined factors that may cause childhood cancer, there is little conclusive evidence for any direct causes (Zahm & Devesa, 1995). This limits the possibilities for prevention and screening measures (Canadian Cancer Society/National Cancer Institute of Canada, 2008). Children are especially vulnerable to treatments such as chemotherapy and radiation, and experience a number of short-term effects such as baldness, nausea, weight-loss or gain (Keene, 2003). In addition to the short-term effects of such treatments, there is also a growing list of long-term effects that may not be as much of a concern to adults. As a result of both the disease and its treatment, childhood cancer survivors are more susceptible to psychological, neurocognitive and physical problems as well (Canadian Cancer Society/ National Cancer Institute of Canada, 2008). Since many of the therapies

used to treat childhood cancer are relatively new, very little is known about their long-term effects. As new treatments continue to be developed, more work must be done to monitor and try to minimize the consequences that the disease and its treatment have on survivors.

Medical Issues Relating to School Re-Entry

The increase in survival rates of childhood cancer and the changes that are taking place in the current medical and educational systems have created the new challenge of developing and implementing hospital-to-school transition plans that accommodate students living with a chronic illness and minimize the effects of their illness (Shaw & McCabe, 2008). Children with chronic illness are at an increased risk for academic and social difficulties. Enskar and von Essen (2008) describe a range of physical problems that children with cancer experience, including fatigue, nausea and hair loss. According to their study, fatigue was the most prevalent physical complaint from children both on and off treatment, which can have a significant effect on a child's school experience. School attendance is also an important issue for children with chronic illness as absences have an effect on academic progress as well as social relations. A study by Cabat and Shafer (2002) indicates that children and adolescents with cancer missed an average of 20 to 45 days of school each year during their cancer treatment. Shaw and McCabe (2008) also note that attendance remains inconsistent for the three years that follow the beginning stages of treatment. In comparison to children with other chronic illnesses, absence is more frequent for children with cancer (Vance & Eiser, 2002). Absences can be attributed to factors such as medical appointments and illness, but may also be a result of fears of being teased and rejected by peers. Suzuki and Kato (2003) explain that 11%

of pediatric cancer patients experience school phobia. This is much higher than the normal 1.7% prevalence rate in the general population and strengthens the need to ensure that psychosocial issues are addressed throughout the school re-entry process.

The Importance of School Re-Entry

As a result of our changing health care system, more hospital services are becoming outpatient services, rather than having patients be admitted for extended periods of time. While in many cases this may be beneficial for patients, it also minimizes the opportunities that children have to participate in hospital-based schooling, and increases the need for children to be reintegrated back into their traditional schools. Despite the many challenges that this creates, Suzuki and Kato (2003) suggest that parents should be encouraging their children to return to their traditional schools as soon as possible. Some of the benefits of returning to traditional schools include the opportunities for interacting with peers and exposure to the socialization processes that are important for school-aged children (Suzuki and Kato, 2003).

Sullivan and colleagues (2001), refer to the return to school as an important factor in re-establishing the daily routines of children with cancer. Having children return to their normal roles is important, as often children with cancer must put their childhood roles and activities aside in order to accommodate the role of being a patient. Bessell (2001) suggests that successful school experiences are an incredibly important factor in maintaining a sense of normalcy for a child and that children want the opportunity to feel normal and be a part of things that they once participated in. Patterson, Holm and Gurney (2004) found that children not attending school experienced sadness from missing normal activities such as school and interacting with friends as well as participation in

extracurricular activities. According to Bessell (2001), children who had good experiences returning to school reported feeling more normal and had better self-perceptions than those who did not return to school or those with less positive experiences. Respondents of Bessell's (2001) study expressed the importance of continuing their focus on education. This focus allowed them to concentrate on something productive other than their disease, while also reinforcing the fact that survival was likely. These are factors that contribute to one's quality of life and should be encouraged and promoted as much as possible. Not only does the return to school have positive effects on the children themselves, Sullivan and colleagues (2001) also indicate that returning to school provides an opportunity for others to understand and cope better with childhood cancer. A better understanding may facilitate more positive interactions between children with cancer and others in the school environment.

Facilitating School Re-Entry

As a result of the many challenges and concerns regarding school re-entry, most childhood cancer treatment centres have established school re-entry programs that focus on facilitating a healthy return to school for children with cancer. "Successful school re-entry is focused on meeting the unique needs of the individual child or adolescent, ensuring continued academic and social skill development by appropriately modifying the school environment, and assisting parents to be effective advocates for their children" (Madan-Swain et al., 1999, p. 322). The roles that each person plays in the reintegration, along with the social support they provide, are all very important determinants of the success of the student (Shiu, 2001). Cabat and Shafer (2002) indicate that these programs generally involve the collaboration of parents, school staff, medical professionals and the

children themselves. Harris (2009) describes an eco-triadic model of educational consultation used for children returning to school following a cancer diagnosis. In this model, Harris (2009) signifies the importance of an educational consultant to facilitate a seamless reintegration into the school system. This consultant coordinates relationships between the home, hospital and school, recognizing their interdependence in shaping a child's school experience. Although the structure of re-entry programs vary, they typically share the same objective, which is to prepare the child, family and school for the child's transition back into the school (Madan-Swain et al., 1999). School re-entry programs focus on all aspects of a child's return to school, including special educational and physical needs. A significant degree of attention is paid to teaching peers about the child's condition and working to dispel any fears or misconceptions that peers may have. The assumption behind such interventions is that knowledge will overcome the fears that children have, which underlie their reactive behaviour towards the child with cancer (Goodell, 1984). Lightfoot, Wright and Sloper (1999) report that a number of students in their study felt that having health professionals visit their school to speak to their peers was helpful. Carefully planned school re-entry programs focus on the particular needs of each individual child and address any issues that may pose a problem throughout the school re-entry process. In addition to this, school re-entry programs also focus on enhancing and supporting protective factors that serve to buffer the many challenges that they face.

Although re-entry programs do vary, Madan-Swain and colleagues (1999) suggest that the school re-entry process should involve three phases. The first phase includes the initial hospitalization and plans for re-entry. During this phase, the medical team stresses

the importance of returning to school to the family. With permission, they would then contact the school to inform them of the student's condition and eventually arrange for the child to continue with homework and preparation for re-entry.

The second phase involves the contact with and education of the school personnel. It is here that teachers are provided with information pertaining to the child's condition and how it may affect his/her educational progress. Following along with this phase, McCarthy and colleagues (1998) evaluated a school re-entry program that involved nurses meeting with the school team to review the child's diagnosis, treatment and side effects that relate to academic progress. In this phase, students are also provided with information relating to the child's condition, and the child is usually given the option to participate in the presentation of information to his/her peers (Madan-Swain et al., 1999; McCarthy et al., 1998; Prevatt, Heffer, & Lowe, 2000). Students are consulted to determine how much information will be shared with their peers. Generally, Prevatt and colleagues (2000) recommend determining the child's own understanding of his/her illness and ensuring that the presentation to the peers matches the child's level of understanding. According to Prevatt and colleagues' (2000) review of school re-entry programs, this phase of educating school personnel and peers can occur three separate ways, with workshops for school personnel, peer education programs, or comprehensive programs that involve both students and school staff. The school personnel workshops usually focus on adults' attitudes toward children with cancer as well as treatment and side effects and often include the emotional impact that this may have on staff. Prevatt and colleagues (2000) found that overall, these workshops often resulted in school staff

feeling more confident in educating a child with cancer as a result of them having a better knowledge base.

Returning to Madan-Swain and colleagues' (1999) phases of school re-entry, the education of staff and peers, as well as the child's return to school, is followed by a third and final phase of follow-up contact. Here, Madan-Swain and colleagues stress the importance of school staff remaining in contact with the family as well as the medical team to discuss ongoing concerns that they have relating to the child's educational progress. The school re-entry process is ongoing. In order for it to be successful, cooperation among all people involved, including medical staff, family and the school is important not only at the point of re-entry but also throughout the child's academic career to ensure follow-up care. Through including all parties involved, as well as incorporating all three phases of the re-entry process, one can be confident that the child's school re-entry will be as positive an experience as possible and schools may once again become a welcoming environment for the child with cancer.

Peers and Social Relationships

When children return to school following cancer treatment, they appear physically different from the way other children remember them looking. This is a result of a variety of side effects from their treatment, which may include hair loss, weight gain or loss and physical deformities resulting from amputation. Fraser (2003) warns that classmates may react negatively to these children because they do not understand that the child is the same person that they were once friends with, and focus instead on the ways that the child with cancer has changed physically. Before returning to school, many children report being worried about their peers' reactions to the changes in their physical appearance

(McCarthy et al., 1998). Children with cancer often experience social isolation and rejection by peers that is similar to the treatment of children with disabilities. Adolescents with cancer have reported feeling isolated from their same age peers (Hokkanen, Eriksson, Ahonen & Salanterä, 2005). The novelty of the child's condition and possible shock that peers experience when a child who has had cancer returns to school can have a negative impact on how they react to that child. Although most students report having positive peer relationships (Bessell, 2001), a number of children have reported being bullied in school, usually as a result of their appearance (Lahteenmaki et al., 2002). Lahteenmaki and colleagues (2002) describe the effect that bullying has on a child by indicating that it contributes to the number of challenges faced by children with cancer when returning to school, therefore making the return to school more difficult than it may have already been. Not having a proper understanding of why children appear physically different may be a cause of the negative peer reactions and have an impact on the child's school experience.

Reactions to changes in a child's physical appearance are not the only factors that affect how peers react to a child with cancer. A number of studies demonstrate that students have many misconceptions regarding chronic illness in general, and cancer in particular (Prevatt et al., 2000; Sigelman, Maddock, Epstein & Carpenter, 1993). Many students believe that cancer is contagious and fear that they will get sick if they interact with a child who has cancer (Prevatt et al., 2000). Fear of contagion is cited as a major factor in why children with cancer are avoided by their peers. Guite, Walker, Smith and Garber (2000) found that children with symptoms of illness are viewed by peers as more sensitive and isolated, and are therefore perceived as less sociable and less accepted than

healthy peers. Information relating to characteristics of cancer, such as how one gets cancer, what some side effects are and whether or not they can catch cancer from a friend, can be helpful for peers. Also, explaining and giving examples of the types of things that a child with cancer can or cannot do may help peers to understand ways in which they can interact with their ill classmate (Prevatt et al., 2000). With comprehensive, age-appropriate information, it is possible that peers can have a better understanding of childhood cancer and perhaps, as a result, be able to develop a more positive and supportive relationship with a child who has cancer.

Social and emotional difficulties have an impact on school functioning as they exacerbate academic and motivational concerns (Shaw & McCabe, 2008). Children who have cancer are reported to be more likely than controls to have no close friends (Barrera, Shaw, Speechley, Maunsell, & Pogany, 2005). With this in mind, it is important to consider that supportive peer relationships play a crucial role in a child's readjustment to the school environment and help to mitigate negative experiences (Lahteenmaki et al., 2002). Literature on school re-entry suggests that success is dependent on peer acceptance (Prevatt et al., 2000). For all children, peers are perceived as the most important support group in helping a child grow and develop appropriately. They are also an important part of a child's school experience (Goodell, 1984; Hokkanen et al., 2005; Suzuki & Kato, 2003). The dependence on peer support is even more important for children with cancer, who may experience feelings of self-consciousness and depression if rejected by their peers (Goodell, 1984). Peers' attitudes influence how children perceive themselves and have a prominent effect on their sense of belonging (Fraser, 2003). Relationships with peers also play a significant role in shaping a child's

perceptions. In a review of literature on children coping with cancer, Suzuki and Kato (2003) note that compared to children who were isolated from their peers, children with higher ratings of peer attachment were found to display higher levels of hope. With this in mind, it is important to consider the quality of children's peer relationships at the point of re-entry and throughout their school experience as these relationships play an important role in shaping the child's school experience.

Social Inclusion

The study of the education of children with medical conditions has generally fallen into two opposing streams (Closs, 2000). There is one that reflects the medical model, attributing difficulties in learning and other areas related to education, such as social and emotional difficulties, to the illness itself. The other is the social model, which attributes many of the difficulties experienced by children with illness to ignorance and a lack of understanding on the part of institutions and society in general. Similar to these two models, Van Eys (1977) describes being cured as having three separate components. The first component, biological, is similar to the medical model, and evaluates whether or not the physical aspects of the disease are cured. Fitting in with the social model are the second and third components, psychological and social cures. The former represents the patient accepting his/her illness while the latter refers to society's acceptance of the individual with an illness, and viewing people who are ill as normal (Van Eys, 1977).

While existing research generally fits into one of the two categories of either medical or social, it is important that we begin to combine the two perspectives in order to attain a more complete understanding of the situation, reflecting all three components of cure. When evaluating the notion of social inclusion, with a particular focus on

inclusion in education, Closs (2000) suggests that when educating children with medical conditions, it is important to take a holistic and individual approach that recognizes each child's unique differences. While maintaining this approach it is also imperative to keep in mind the importance of including children with their peers in both social and academic settings. This approach acknowledges both the medical and the social perspectives and stresses the need to combine the two positions of focusing on the individual and his/her medical and psychological needs as well as the social and institutional structures necessary to provide a more authentic form of inclusion. The present research focuses on the notion of inclusion using this holistic approach and thereby includes both social and academic features that either promote or hinder a child's full inclusion in education and the school system.

In discussing parental concerns regarding the education of children who are ill, Closs (2000) highlights parents' desire for schools to not only provide a good academic education for their children, but also to serve as a distraction from their illness or a compensation for the negative experiences the child has endured as a result of his/her illness. In this sense, friendship and social factors, in addition to academic factors are key determinants of the quality of a child's inclusion and integration into age appropriate grades in education.

Cognitive and Academic Effects of Childhood Cancer

With regard to the school experience, childhood cancer does not only have an impact on a child's social and emotional development, but it has also been shown to have an effect on a child's cognitive functioning. Barrera and colleagues (2005) found that in comparison to controls, childhood cancer survivors were more likely to have poorer

academic outcomes as indicated by receiving special education support and repeating a grade. Childhood cancer survivors have a higher rate of repeating a grade when compared to their siblings, with these rates being higher for children who were in high school at the time of diagnosis (Bonneau et al., 2011). Upon returning to school, children who are experiencing problems with their academic achievement are likely experiencing the late effects of their treatment (Mulhern & Palmer, 2003). These late effects are associated with brain damage as a result of radiation and chemotherapy, which are commonly used to treat childhood cancer (Armstrong & Mulhern, 1999; Lahteenmaki et al., 2002; Mulhern & Palmer, 2003).

When evaluating the cognitive and learning consequences of cancer, it is important to consider the intensity and type of treatment that each individual child has undergone (Armstrong & Mulhern, 1999). Research indicates that children who have received cranial irradiation therapy have demonstrated the most dramatic and consistent cognitive impairments (Barrera et al., 2005; Espy et al., 2001; Herrmann, Thurber, Miles & Gilbert 2011). Barrera and colleagues (2005) specify that academic challenges were most evident in math, followed by English and science. Espy and colleagues (2001) also found declines in academic arithmetic, verbal fluency and visual motor skills, with challenges associated with visual motor skills being particularly problematic. Other common neuropsychological problems experienced by childhood cancer survivors include problems with attention, memory, mental processing speed, and intellectual deterioration (Armstrong & Mulhern, 1999; Herrmann et al., 2011). These changes develop slowly, with difficulties generally not appearing until two to four years following treatment (Herrmann et al., 2011; Mulhern & Palmer, 2003). While the effects of

treatment vary, the first noted changes are often as simple as a slower pace of completing homework and other assignments (Mulhern & Palmer, 2003).

The course of treatment for the two most common forms of childhood cancers, Acute Lymphoblastic Leukemia (ALL) and brain tumours, illustrate the potential for negative cognitive impact (Armstrong & Mulhern, 1999; Mulhern & Palmer, 2003). ALL is a blood cancer that usually requires three phases of chemotherapy. This type of cancer is also known to spread into the central nervous system (CNS), and as a result, chemotherapy treatment into the cerebrospinal fluid is also common (Armstrong & Mulhern, 1999). Certain drugs used to treat ALL are known to have acute side effects such as mood swings and marked irritability, as well as slower reflexes and declining fine motor speed (Armstrong & Mulhern, 1999). Although these changes are not directly related to cognitive functioning and academic progress, they can have profound implications for children's functioning within a class setting, therefore affecting their ability to learn. In addition to the acute effects of treatment, some drugs such as methotrexate, are related to an increased risk of neurological damage and neurocognitive impairment. Treatment for brain tumours is similar and usually also involves surgery to remove the tumour as well as cranial radiation therapy (CRT) which also effects cognitive functioning (Armstrong & Mulhern, 1999; Lahteenmaki et al., 2002; Mulhern & Palmer, 2003). Although treatment options for childhood cancers have changed over time in an attempt to improve survival rates as well as reduce the late effects associated with them, Armstrong and Mulhern, (1999) indicate that newer treatments may still result in brain changes.

There are many factors that contribute to variability in the effects that the treatment has on survivors. Treatment related effects include the type of cancer or tumour, the use of radiation and the dose of radiation or chemotherapy that the child receives (Armstrong & Mulhern, 1999). The differences in treatment doses and types can have a significant effect on the severity of implications that a child experiences. Another common risk factor is age, with children treated at an earlier age being at higher risk (Armstrong & Mulhern, 1999; Herrmann et al., 2011; Lahteenmaki et al., 2002; Mulhern & Palmer, 2003). Although it is not certain, it is hypothesized that this higher risk is a result of the fact that developing brains are more sensitive to the treatment and the damage that it may cause (Mulhern & Palmer, 2003). Armstrong and Mulhern (1999) point out that, in cases where cognitive late effects have been found, functions associated with brain structures that had developed prior to treatment remained intact and impairments were usually seen in functions associated with areas of the brain that did not develop until after the child had completed his/her treatment. The final common risk factor is gender, with girls exhibiting a higher degree of late effects (Armstrong & Mulhern, 1999; Mulhern & Palmer, 2003). This is usually found with respect to verbal and language processing. Although researchers are not certain why females are at a higher risk, it is speculated that hormones may play a role in differentiating them from males (Mulhern & Palmer, 2003).

The biological and physical risk factors associated with treatment and its cognitive late effects provide substantial evidence to indicate the need for researchers to continue to focus on the effects that cancer and its treatment have on its survivors as well as ways to mitigate these effects. Mulhern and Palmer (2003) note that even for cases that

were matched for the same diagnosis, treatment and age at treatment, there were still differences in cognitive performance, therefore suggesting that the environment also plays a role in determining the degree to which a cancer survivor may experience cognitive late effects. Research suggests that the combination of the disease, its treatment and other situational factors work together to impact a child's educational outcome (Barrera et al., 2005; Bonneau et al., 2011).

Although there is not much that can help mitigate the physical and biological consequences of treatment, the indication that the environment may play a role in modifying these effects suggests that there are options that can be undertaken to help survivors. Espy and colleagues (2001) suggest that children with cancer would benefit from educational support to mitigate the negative effects of their treatment. A number of students in the study by Lahteenmaki and colleagues (2002) indicated that they needed extra tutoring at school. Findings suggest that a lack of tutoring was seen as a common problem for these participants. According to Lahteenmaki and colleagues (2002), more funding should be allocated for tutoring children with chronic illnesses in order to optimize their education and academic potential. Kim and Yoo (2010) discuss the concept of resilience and indicate that cancer survivors who reported having higher family functioning and positive relationships with their teachers and friends were more resilient. These positive relationships were found to have a greater influence on resilience than demographic factors such as age and gender (Kim & Yoo, 2010). If the environment can be modified to assist families in meeting the demands that the disease has imposed on their lives and include extra tutoring to help minimize the educational implications that

the treatment of cancer has on children's cognitive processes, one may assume that the educational experiences of these children would be improved.

Special Education in Ontario

Not only have the past 50 years marked an increase in survival rates for childhood cancer (Eiser, 2004), but they have also been credited with the coming of age of special education (Bennett, Dworet & Weber, 2008). The increase of awareness of and services for children who require special educational assistance is the result of a movement toward, "educating children with special needs according to those needs" (Bennett et al., 2008, p. 9). The Ministry of Education (2001) defines an exceptional pupil as "a pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program" (p. A3). In Ontario, special needs are defined using a categorical approach that identifies students as having behaviour, communication, intellectual, physical or multiple concerns (Bennett et al., 2008; Ministry of Education, 2001). There is a current debate over the standardized categories and definitions used within the province, as a number of parents and advocacy groups feel that they are too exclusive. With the official categories and definitions of exceptionality being the key factor in determining which students are identified and assigned to receive special education resources, Bennett and colleagues (2008) explain that the Ministry is receiving criticism over the lack of updates to a seemingly out-dated list.

One major challenge posed by the rigid definitions is that in most cases, it is difficult to describe students with special needs. According to Bennett and colleagues (2008), as each individual is unique, many students fit into a number of definitions and

categories, while at the same time, some students may fall into the cracks between the definitions, therefore making it difficult for them to be identified and receive support. Parents and children with cancer seem to be faced with this same predicament in that a cancer diagnosis itself does not fit into any of the categories of exceptionality listed by the Ministry. While most children experience late effects of the treatment that interfere with their educational abilities, their needs do not clearly fit into the categories, making it difficult for most families whose children require special education services to acquire the necessary resources.

In addition to their educational needs, many children with cancer also return to school with special health needs. There is a common misconception that students with health needs automatically require special education services. Generally, for children with cancer as well as children with other chronic health conditions, it is the effect of the health condition that requires special education programming rather than the condition itself (Bennett et al., 2008). In cases where students experience a prolonged medical absence, as is often the case with children with cancer, education professionals recommend that schools and families begin to prepare for the student's return to school in advance. Preparing staff and students can be helpful in terms of raising awareness of the student's condition as well as ensuring sensitivity to their needs (Ministry of Education, 2001). The Ministry of Education (2001) outlines a number of education alternatives for facilitating a smooth transition back to school that includes a gradual integration that slowly eases students back into the school setting as well as the sharing of documents and regular communication between the school and parents. Similar actions have been taken in school re-entry programs that children with cancer receive. In these situations, the

importance is placed on meeting the needs of the students, whether it is through remedial sessions or shortening the school day. Bennett and colleagues (2008) explain that teachers are encouraged to be familiar with the characteristics and implications of the student's health needs in order to ensure that educational services and programs are appropriate to those needs.

With regards to special education provision in Ontario, there is a hierarchy of responsibility as laid out by the Ministry of Education that begins with the Ministry and works down to assigning roles and duties to parents. In Ontario, the Ministry of Education provides school boards with an overall amount of money to be used for special education services. A Provincial Advisory Council on Special Education is also established to advise the Minister of Education. It is the Ministry that sets out the regulations and policies and provides the standards and categories for special education (Bennett et al., 2008; Ministry of Education, 2001). From that, individual school boards are responsible for complying with the Education Act and are required to establish the Identification, Placement, and Review Committee (IPRC) and Special Education Advisory Committee (SEAC). School boards are also responsible for ongoing staff development to ensure that they are up to date on special education needs and services. School principals are responsible for communicating board expectations to staff. It is the principal of each school who is to ensure the identification and proper placement of children with special education needs, as well as facilitate the effective delivery of special education programs (Ministry of Education, 2001). Classroom teachers and specially trained special education teachers are responsible for providing the program outlined for the students. This may involve modifying teaching styles and practices including the

methods used to assess student achievement. The role of the parent, as outlined in the Ministry of Education's Teachers Guide for Special Education, gives them a formal position in working with the teacher and the principal to solve problems and to participate in the development of their child's Individual Education Plan (IEP). The involvement of all levels of education professionals as well as parents indicates the path through which parents must navigate to receive special education services for their child. Having all levels involved also illustrates the importance of special education in Ontario and the need to have students' special education needs met as effectively as possible.

Through having an understanding of special education regulations in Ontario, one can better appreciate the journey through which children with cancer and their families must travel in order to reduce the negative implications that their illness and its treatment have on their educational experiences and attainment. Childhood cancer and many of the negative implications that the disease and/or treatment have on a child do not fit into one of the categories of exceptionality. The ways in which children are affected by the disease and/or treatment vary, therefore allowing some children to be easily identified while others may not be. The restrictive special needs categories outlined by the Ministry of Education exacerbate parents' stress of having to advocate in order to attain the necessary resources for their children to achieve academic success.

Teachers

According to childhood cancer survivors, teachers are seen as the most important people in creating a successful school environment (Bessell, 2001). Lightfoot and colleagues (1999) indicate that students' relationships with their teacher have a big impact on their experience, with students stressing the importance of having a teacher

who understands them and their situation. In cases where childhood cancer survivors reported poor relationships with their teachers, issues of fairness, such as not being given extra time to complete tests or a lack of appropriate modification in teaching methods, were cited (Bessell, 2001). Having a teacher understand them is viewed as crucial for receiving appropriate educational support (Lightfoot, Mukherjee & Sloper, 2001). Participants in Bessell's (2001) study reported that most teachers who were helpful had had their own experiences with cancer or with someone who had had cancer and attributed that to why they were so helpful and understanding, rather than to training provided by the school or medical staff.

Support from teachers is reported to vary even within the same school. The extent of appropriate support from teachers is dependent on the level of awareness and understanding that the school staff has of a student's condition as well as the attitudes that they possess (Madan-Swain et al., 1999; Mukherjee et al., 2000). In addition to their awareness, the visibility of illness, such as baldness or use of assistive devices for example, was seen to influence teachers' willingness to believe that a student is ill. This was reported by students, parents and teachers themselves in Mukherjee and colleagues' (2000) study. Teachers are also responsible for the education and well being of all students in their class and McCarthy and colleagues (1998) indicate that upon the re-entry of a child with cancer, teachers may be overburdened with juggling between the importance of the ill child and the class as a whole.

A major problem cited by teachers is their lack of knowledge and the difficulty in obtaining health related information (Madan-Swain et al., 1999; Mukherjee et al., 2000). This lack of appropriate knowledge resulted in teachers being anxious and unsure of how

to approach students with chronic illness (Eiser, 2004; Madan-Swain et al., 1999). The difficulties in obtaining information appear to be greater in secondary schools as a result of there being more people involved (Mukherjee et al., 2000). With students having multiple teachers as opposed to just one, the delivery of information must be much more widespread, requiring a great deal of coordination. Having a liaison who is responsible for coordinating the delivery of information as well as making special arrangements for students and communicating this with school staff has been suggested (Eiser, 2004; Harris, 2009; Mukherjee et al., 2000). The importance of this role and the amount of time required for its proper delivery would likely require that this liaison have an adequate amount of non-teaching time as well as a substantial amount of training related to educating students with chronic illness (Mukherjee et al., 2000). The importance of having teachers be well informed is highlighted by Madan-Swain and colleagues (1999) as they suggest that teachers require specific information about a student's illness and how it affects his/her development and academic performance in order to create a reinforcing classroom. With this information, teachers can adapt their instruction to the child's abilities and therefore facilitate greater academic success. By having a teacher who understands the child's situation and makes an effort to assist the child, one can speculate that the relationship between the two would be quite positive, therefore increasing the probability that the child will have a positive school experience both academically and emotionally.

Parents' Experiences of School Re-Entry

Following the initial shock of a cancer diagnosis, parents generally look forward to and encourage their child to return to school. For many, having their child return to

school is a way for parents to envision their child having a future (Sullivan et al., 2001). Parents also find that returning to school is a way to regain the feeling of normalcy in their lives and is valuable to their child's recovery as it allows them the opportunity to interact with peers and to focus on other productive things as a distraction from their illness (Mukherjee et al., 2000; Sullivan et al., 2001). Having one's child return to school following diagnosis is a highly emotional time, with both the encouraging factors, as well as those that may make parents hesitant to send their children to school, influencing their decisions.

Although parents are generally happy and eager for their child to return to the normalcy of school, many parents have fears and anxiety that may make them reluctant to do so, or cause them to be overprotective. Many parents experience anxiety about their child being teased as a result of the physical changes associated with his/her illness (Eiser, 2004; Madan-Swain et al., 1999; McCarthy et al., 1998). In addition to social concerns, most parents report being concerned for their child's health and safety when returning to school, with fear of infections being cited most often (McCarthy et al., 1998; Sullivan et al., 2001). At the point of initial re-entry, most parents do not seem overly concerned with academics (Eiser, 2004; McCarthy et al., 1998) and focus mostly on the physical and social aspects of re-entry.

For these reasons, having the child return to school can be a very stressful time for parents, and respondents in Patterson and colleagues' (2004) study indicated that they often felt that they now had to advocate for their child at school in addition to doing so within the hospital. Close contact with school personnel is viewed as a necessary and successful way to reassure parents during this process and reinforce their support in

having the child return to school (Madan-Swain et al., 1999; Sullivan et al., 2001). With this frequent reinforcement and successful re-entry programs, most parents report a positive experience of their child's school re-entry (McCarthy et al., 1998). Once the child was back into the routine of attending school, parents remained slightly worried about their child's health and safety, yet seemed to feel less worried about teasing and began to focus more on their child's ability to keep up with school work (McCarthy et al., 1998). With parents and children experiencing a positive school re-entry, parents can begin to feel more relaxed and focus more on their child's academic and social success.

Siblings' Experiences

When trying to gain an understanding of the cancer experience, it is crucial that one does not overlook the experience of, as well as the role played by healthy siblings. For a child with cancer, the impact that the diagnosis has on his/her healthy sibling, as well as the way in which they interact with and relate to each other, is a key factor in shaping the cancer experience. As Patterson and colleagues (2004) indicate, understanding outcomes in one's quality of life requires one to consider the reactions and state of other members of the family. Patterson and colleagues (2004) note that according to family systems theory, "what happens to one family member affects the other members" (p. 391). In this case, it is important not only to understand that siblings are affected by a diagnosis of cancer, but also that the effects that the diagnosis has on them, also has an effect on the child with cancer, as the entire process is circular. In discussing the involvement of siblings throughout the cancer experience, Woodgate (2006) notes that when considering the enduring nature of the sibling relationship, the lack of involvement throughout a sibling's cancer experience may have a negative impact on

one's social development. Eiser (2004) also highlights the importance of understanding the sibling experience as a result of the close nature of the sibling bond, outlasting most other relationships. Nolbris, Enskar and Hellstrom (2007) signified the longevity of the sibling relationship as they found that siblings indicated that their brother or sister meant more to them than their friends. As a result of the unique perspective that siblings offer, Murray (2002) suggests that siblings have much to contribute to meeting the needs of the child with cancer as well as the parents and themselves, thus highlighting the need for an understanding of their experience.

Scholars have pointed to the limited information regarding siblings in existing literature (Eiser 2004; Murray 2000; Murray 2002). This can have many negative consequences, as without having an understanding of their experiences it is quite possible that their needs are not being met. Eiser (2004) and Murray (2002) note that a majority of current literature regarding siblings comes from the perspective of the parents rather than from the siblings themselves. Murray (2002) suggests that the lived experience of a sibling of a child with cancer provides insight that cannot be attained simply from speaking to parents. In addition to this, Eiser (2004) notes that in some instances, parents seem to report more negative implications of the disease, whereas the siblings themselves seem to provide more variable responses. Since the cancer experience affects the entire family, and because of the varying perspectives held by each family member, Eiser (2004) recommends that research with siblings be conducted using a family centered approach.

The importance of using a family centered approach is highlighted by the extent to which the cancer experience has an effect on changing the dynamics of a family,

regardless of its size. Patterson and colleagues (2004) note that as cancer rates are highest in the first year of life, many parents are often in the beginning stages of the family life cycle, making it increasingly difficult for them to cope with even simple, more routine challenges. Numerous studies discuss the notion of a loss of a normal family life as a result of the demands associated with the diagnosis and treatment of childhood cancer (Alderfer et al., 2010; Eiser, 2004; Murray, 2000; Murray, 2002; Patterson et al., 2004; Woodgate, 2006). When speaking to parents regarding the effect of the cancer diagnosis, Patterson and colleagues (2004) report that, “they talked about how the cancer invaded everything about their lives and how they felt like they were in a different world” (p. 397). Woodgate (2006) furthers this notion by stating that the cancer experience impacted all things that contribute to family life, including roles, responsibilities, events and routines. In relation to this disruption in families with a chronically ill child, general family issues, such as fairness for example, can become more of a problem than they may be in families without illness (Eiser, 2004). Murray (2002) attributes the disruption of the family structure to the fact that parents are faced with the stress of allocating time to both healthy and ill children as well as the division of time spent in the home versus at the hospital. The illness and its treatment must be integrated into their lives and the demands of the illness result in immense burdens on all members of the family (Murray 2000). Siblings of children who have had cancer reported that during non-intensive phases of treatment, their lives had felt similar to the way they used to prior to their sibling being diagnosed, however they also indicated that their lives were forever changed as a result of the illness (Nolbris et al., 2007). Similarly, in their review of existing literature, Alderfer

and colleagues (2010) note that siblings appeared to experience less distress as time passed following treatment.

The interruption of normal family life has a profound effect on siblings. Eiser (2004) notes that distress about family separations and disruptions to normal activities are a leading cause of emotional problems in siblings of children with cancer. Alderfer and colleagues (2010) identified a loss of status within the family and a change in family relationships as common themes in the existing literature. Woodgate (2006) found that siblings experienced “a struggle to maintain a sense of being within their families” (p. 412) as a result of the cancer experience. In addition to this, siblings also noted the loss of their family’s way of life and a loss of themselves within the family (Woodgate 2006). In describing the loss of sense of self within the family, Woodgate (2006) found that siblings often used the experiences of their ill sibling and parents to define their world and experiences, therefore implying that they are secondary characters in their own lives and within their families. Similar to this, Eiser (2004) explains that when describing their experiences, siblings focus more on the ill child rather than on their own feelings and concerns.

The cancer experience and its related demands appear to have a variety of effects on healthy siblings. While some research shows that siblings experience negative effects, there is also research that highlights a number of positive changes, as well as data that find little to no effect on siblings’ well-being. In their review of existing literature, Alderfer and colleagues (2010) concluded that the poorest adjustment was found in adolescent siblings of a child with cancer, also noting that female siblings exhibited greater levels of distress than males. With regard to some of the more negative effects, a

number of studies found that a lack of adequate communication regarding their sibling's illness is a key determinant of negative feelings and adjustment difficulties. Eiser (2004) suggests that communication within the family is important as it is often identified as a key component in moderating the sibling relationship. Gardner (1998) found that siblings found it helpful when parents spent time answering their questions. In opposite cases, where questions go unanswered, studies show that siblings begin to feel isolated from their families (Murray, 2000; Murray 2002). Having unanswered questions can also lead to the development of fears and misconceptions, therefore highlighting the importance of providing healthy siblings with age appropriate information regarding their brother or sister's condition (Eiser, 2004; Murray, 2002). Siblings were reported to be constantly worried about their brother or sister, wondering about the prognosis of his/her disease and what might happen to him/her (Nolbris et al., 2007). In addition to fears and misconceptions, a number of siblings studied indicated that their needs were not being met and that they felt less cared for, and in some cases, forgotten (Murray, 2002). In turn, this resulted in a diminishing sense of security (Alderfer et al., 2010; Woodgate, 2006), which may have negative implications with regards to their adjustment and well-being.

In contrast to the adverse effects on siblings, a number of positive changes are also reported in current literature. Woodgate (2006) found that siblings demonstrated "a resilient nature and determination in their commitment to protecting their family" (p. 412). This commitment and determination were made evident through siblings reporting that they would often assume additional chores and responsibilities. They also expressed the desire to protect their parents and ill siblings from pain. Nolbris and colleagues (2007) also found that siblings' roles had changed to include a caring or protective role. Siblings

indicated that they were supportive of their brother or sister who was ill and protected them in situations of conflict with peers. Overall, most participants in Woodgate's (2006) study indicated that the cancer experience strengthened their family bonds and brought their families closer together. Gardner (1998) and Eiser (2004) also found that siblings felt responsible for their ill sibling's health, with older siblings often taking on more responsibility. Siblings reported a conflict between their own interest and the needs of their brother or sister who was ill and the difficulty in being kind to their sibling despite the extra attention that the sibling was receiving from parents (Nolbris et al., 2007). Many siblings of children with cancer have been shown to have an enhanced sense of maturity and compassion as well as a greater appreciation for life (Alderfer et al., 2010; Eiser, 2004; Murray, 2002). Having an understanding of the positive effects that siblings experience is important for ensuring the amelioration of these outcomes as well as for creating avenues through which other siblings of children with cancer can experience them as well.

The variability in findings related to the effects of the cancer experience on healthy siblings points to the need for continuing research involving siblings. It is imperative that we have a more complete understanding of their needs. The existence of negative effects indicates the need for psychosocial support for siblings, tailored to their own perceived needs. Murray (2002) suggests that having social support available can help siblings of children with cancer by minimizing the impact that the disease has on them and their own lives. Through understanding siblings' needs and working towards providing adequate resources and support, we can work towards increasing the positive effects of the experience while at the same time having the adverse effects of the cancer

experience minimized for siblings, and in turn, also reduced for other family members and the ill child as well.

Rationale and Research Question

For children and adolescents, the school experience is critical to healthy social, emotional and educational development. Returning to school following cancer diagnosis and treatment is considered a milestone for children and is viewed as an integral component of survivorship (Sullivan et al., 2001). With the increasing focus on the psychosocial aspects of childhood cancer, Sullivan and colleagues (2001) discuss the importance of school re-entry on social survival to the importance of treatment on physical survival. Understanding the educational and social outcomes of school-aged childhood cancer survivors plays an important role in the development of interventions and services designed to help facilitate healthy development through the process of school re-entry. Understanding how childhood cancer survivors and their families feel about being in school, and how they experience it, is important in informing the development of programs to assist with this process.

The main focus of the present study was to answer the broad question of how childhood cancer survivors and their families describe their experience of the return to school following their diagnosis and/or treatment. In order to address this question, four specific areas were examined including cognitive and academic concerns, social issues, perceived support, and the impact on siblings.

It is important to understand whether or not children's academic progress has been affected as a result of their illness or treatment. The degree to which children and families experienced cognitive and academic difficulties was examined in order to gain

an understanding of the impact that the illness has on their academic progress.

Understanding the academic challenges that these children face when returning to school can provide us with a better idea of their needs. This can highlight an area for future research aimed at determining ways to assist children with cancer overcome these challenges and increase their chances of succeeding.

The present study also examined the nature of peer relationships throughout and following the school re-entry process by investigating the level of peer acceptance that the children experienced, as well as whether some families experienced a change in the nature of their children's peer relationships. As peer relationships have a profound effect on a student's quality of life and school experiences, it is important to gain an understanding of how these relationships are affected when a child returns to school following cancer treatment

The effectiveness of any school re-entry services available to the families is also an area that was explored in this study. Along with this, the study also sought to examine the degree of support that families perceived was available to them in terms of assistance from both the school and outside resources. Being aware of participants' perceptions of the quality of support is important in understanding what the needs of the families are and could be useful in further research regarding support services and agency/school resource allocation in the future.

Finally, in addition to understanding how the children themselves experienced the return to school, this study also examined how siblings are affected throughout the process. The sibling experiences came from the perspective of the parents and addressed whether the siblings received any special forms of support throughout their brother or

sister's illness and return to school, as well as whether or not they experienced any adjustment issues. In addition to this, the study focused on whether siblings experience a change in their relationships both with their brother or sister who has cancer as well as with their peers. Having an understanding of how siblings are affected by childhood cancer and the return to school of the child who is ill is important as this information may indicate the extent to which special attention should be paid to assisting siblings during this process. As siblings have a profound impact on each other's lives, it is important that both the healthy and ill siblings' experiences be considered.

It is through examining these factors that we can develop a more complete understanding of what it is like for families and for children with cancer when they return to school following their diagnosis and treatment. A better understanding of these experiences will help to identify areas that may be of concern or that require attention as well as those that seem to be effective in enhancing the school experience and therefore contributing to a higher quality of life for both the cancer survivors and their families.

The Researcher's Role

As in all qualitative studies, the role of the researcher is an important consideration to be addressed (Creswell, 2003). It is important to note that I am not a cancer patient/survivor. Although I have one grandparent who has survived cancer, I appreciate that the experience is very different from that of a child battling cancer. I recognize that this lack of familiarity limits my ability to fully understand and speak of the experiences of the children and their families. In light of this, when discussing her own experience as a mother of a chronically ill child and also a professional who works with families of chronically ill children Burnett (2000) points out that a person cannot

fully comprehend the intensity of emotion that children and families experience in situations where a child is chronically ill. My lack of familiarity with chronic illness further underlines the need for me to be aware of these differences in my interpretations and to do my best to collect and represent the data in as honest and truthful a way as possible.

Despite not sharing these experiences with my participants, I do have a personal connection with children who have cancer and their families. As a volunteer for Camp Trillium, I have worked in the clinic at McMaster Children's Hospital and Credit Valley Hospital for a total of three years, where I had the opportunity to interact with the patients and their families and to gain a general understanding of the clinic atmosphere. As the location of the parent support group from which participants were recruited is far from either of these clinics, I had not already met or established relationships with any of my participants. This allowed me to develop my relationship with the participants with a clean slate, as I was meeting them for the first time and therefore did not have any preconceived notions or information about their situations.

It is important to note that at the time that the study was conducted, my experience with the topics examined in this study were limited to my volunteer work with Camp Trillium. In the time that had elapsed between the data collection and data analysis phases, I have completed a Bachelor of Education degree and have become increasingly familiar with the school system and the ways in which special education services are delivered to students. I strived to ensure that my own experiences and knowledge did not overshadow the participants' accounts, and aimed to deliver an accurate account of their experiences.

Method

Data Collection Procedures

As noted by Creswell (2003), participants and sites for qualitative research are purposefully selected as those that will best help to illuminate the issue being studied. The setting in the present study was chosen primarily for reasons of convenience and feasibility. The site used was an ongoing peer support group where parents from the surrounding area gather to share their stories and learn about issues pertaining to their child's battle with cancer. The parent participants in this study were familiar with the setting and have a child who had cancer while attending school. The primary component of the study consisted of a focus group with parents. This focus group was conducted during a regularly scheduled meeting of the childhood cancer support group in a municipality in Southern Ontario. The group meets monthly to share their experiences. The use of this pre-existing group was chosen for convenience purposes, but was also beneficial in that the members of the group were already aware of each others' situations and experiences and therefore might have been more comfortable sharing their stories. Rather than having to allow for time to get to know each other, this pre-formed group already had an established caring and supportive environment. Kitzinger (2006) suggests that a pre-formed group may allow for research participants to relate to each others' comments and be more willing to share and discuss in a way that resembles their natural conversations.

In addition to the focus group, follow-up interviews with participants who wished to participate further and/or their children took place either in a pre-arranged meeting area, the homes of the participants, or via telephone for families who were not able to

meet in person. While face-to-face interviews were the preferred method of data collection, it was understood that families dealing with the stresses and challenges associated with having a child who has a serious illness such as cancer, may not have been able to afford the time required for a face-to-face interview. As telephone interviews were more flexible to schedule and when needed, reschedule, they were provided as an option to respect the needs of the participants and to help make it as convenient as possible for them. The exact timing of the interviews was coordinated with the families in order to ensure that they were convenient for the participants and did not impose any more disruption than necessary.

Participants

The participants in this study were 16 parents of childhood cancer survivors who had returned to school following diagnosis and/or treatment. In addition to this, in cases where both parents and children were willing, two children, aged eight and sixteen, and one twenty-eight year old adult who had survived childhood cancer were also involved. Children were involved as a part of the study as they are the primary actors in the cancer experience. The decision to include the childhood cancer survivors in the study was based on the fact that the views of ill children are substantially lacking in the existing literature regarding the school experiences of children with illness (Lightfoot et al., 1999). Closs (2000) highlights the fact that parents and children might have different interpretations or feelings regarding the illness experience, and therefore both points of view are important. For the purpose of this study, parents' accounts were the primary source of information, with interviews from children being used as an extension to the stories told by the parents. While children with cancer and their siblings were invited to participate in the

study, only three cancer survivors were available to be interviewed. Unfortunately, none of the parent participants indicated that they wished for their other children to participate in the study, therefore no sibling interviews took place.

Participant selection and recruitment.

The selection process for these participants was non-random as they were conveniently recruited from a regional parent support group in Ontario that meets on a monthly basis. The group coordinator was contacted and provided with information regarding the study. Upon approval from the coordinator, all participants were recruited through this support group.

In all, 19 people participated in the study. Of these 19 people, two were female childhood cancer survivors aged eight and sixteen and one was an adult male childhood cancer survivor aged 28. Sixteen parents of children who have had or have cancer participated in the study. Twelve were mothers and 4 were fathers. Of this group of parents, there were three couples who represented one child each. Overall, the experiences of 14 children and families were represented in the study. Thirteen families were represented by parents and one family was represented by the adult survivor of childhood cancer.

Table 1: Focus Group Participants

Participants	Number
Mothers	12
Fathers	4
Adult Survivor of Childhood Cancer	1
Total Participants	17
Total Experiences Represented	14 ¹

Table 2: Parent Interview Participants

Participants	Consented	Participated
Mothers	6	3
Fathers	3	3
Total Participants	9	6 ²
Total Number of Interviews Conducted	6	5 ³
Total Experiences Represented	7	4 ⁴

Table 3: Childhood Cancer Survivor Interview Participants

Gender	Age at Diagnosis	Grade at Diagnosis	Age at time of Interview	Grade at time of Interview	Diagnosis
Female	4	Pre-School	8	2	Leukemia
Female	10	4	16	10	Brain Tumour
Male	Unknown (Approx. 4)	Unknown	28	N/A	Brain Tumour

¹Of this group of 16 parents and one adult survivor of childhood cancer, there were three couples who each represented one child; therefore only 14 experiences were represented in the focus group.

² Three mothers who consented to participate in the interviews were withdrawn from the study. Of these three, one could not be reached through the contact information that was provided, one experienced the death of her child and could not be contacted and the third did not attend the scheduled meeting time and could not be contacted to reschedule.

³ Two parents (one couple) of the same child requested to have their interview conducted as a single interview rather than two separate interviews.

⁴ Of the six parent interview participants, only four experiences were represented as there were two couples that each represented one child, therefore reducing the number of experiences represented to four.

Focus group.

The primary type of data collection took the form of a focus group. The use of the focus group was selected based on the notion that a focus group allows the researcher to gather information based on communication among the participants. Kitzinger (2006) points out that focus groups allow people to share with each other and ask questions and make comments based on each other's experiences. Considering the sensitivity of the research topic and the degree of emotion attached to the experiences, Kitzinger (2006) also suggests that the focus group dynamic might help in facilitating the discussion as members of the group who are less inhibited may be helpful in breaking the ice for those participants who are less inclined to share.

The information discussed in this meeting was selected based on information gathered from existing literature regarding school re-entry and social integration. The focus group was recorded using a video recorder to ensure accuracy during the transcription process. Prior to their monthly support group meetings, members were informed of the study and invited to participate during the time of the meeting. This time had been allocated by the coordinator of the support group, therefore minimizing any inconvenience for the participants. This meeting was guided by a set of open-ended questions regarding the parents' experiences of having their child return to school as well as school related areas of concern for them.

A total of 17 people participated in the focus group. Included in this group were three couples (three mothers and three fathers), nine mothers, one father and one adult survivor of childhood cancer. Although the focus group was intended for parents only, the adult survivor who did attend was invited to stay out of respect for his/her wish to

share his/her experiences. It was anticipated that 10-15 parents would be in attendance based on previous attendance at the support meetings. Although the number of people in attendance was larger than would be in most focus groups, all participants were included as there were no other opportunities to have numerous meetings with smaller groups. Participants in the focus group had children with a variety of different types of cancer and were also at different stages of the cancer experience. Some families had been in remission for a long period of time and were speaking retrospectively. Of these, three of their children were in high school. One had been diagnosed as an infant and the other was diagnosed in the fourth grade. Two of the children who were spoken of in retrospect were in elementary school at the time of the focus group. One child was diagnosed during preschool and the other had been diagnosed relatively close to the time of the focus group. Of the families with children still receiving treatment, two children were in elementary school and one child was in high school. The exact time and stage of schooling that these children were diagnosed is unknown. In addition to the adult survivor of childhood cancer who attended the focus group, one family spoke about their experiences with their child who is now an adult and had navigated through the school system right through university. The child of one participant was terminally ill and therefore no longer attended school at the time of the study. Three other participants attended the focus group but did not specify their child's age or the stage of their illness trajectory.

Those who attended the focus group were provided with information regarding the study and were asked to sign a consent form indicating their understanding of the process and willingness to participate. This consent form can be found in Appendix B. In

addition to consenting to participate in the focus group, participants were asked to indicate on the form whether they would like to be contacted to participate in a follow up interview. Finally, the consent form also asked for parents to indicate whether they would agree to their children being contacted for a similar interview. Child interview invitations included both the child with cancer and his/her healthy siblings. A total of nine parents agreed to participate in a follow up interview and four gave consent for their child with cancer to be contacted for an interview. None of the consent forms indicated consent to contact healthy siblings of children with cancer, therefore sibling interviews did not occur as a part of this study.

Interviews.

Parent interviews.

The second form of data collection was individual interviews used as a way to capture the experiences from the participants' perspectives. These interviews were semi-structured and focused on their feelings and opinions of the their child's illness and return to school. As suggested by Woodgate (2005) the questions asked during the interviews were open-ended so as to allow for participants to use their own words to describe their experiences and what they feel matters the most to them. As stated by Britten (2006), open-ended questions present the area to be explored and allow the interviewer or interviewee to diverge in order to pursue an idea or theme further. The open-endedness of the questions was also chosen in an attempt to avoid imposing any assumptions on the participants' experiences and accounts, as highlighted by Britten (2006). The content of the interviews was similar to that of the focus group, but also included questions based on information shared during the focus group in order to gain a better understanding of how

each participant is affected by certain events and experiences. Focus group questions can be viewed in Appendix C, parent interview questions are provided in Appendix D and childhood cancer survivor interview questions are located in Appendix E. These interviews served as triangulation for the focus group data. One-on-one interviews also provided an opportunity for participants to share any information that they may not have felt comfortable discussing with the group

Attempts were made to contact all parents who agreed to participate in the follow-up interviews. Despite many attempts to reach them, two of the parents could not be reached and one parent missed two scheduled interviews. Two parents of the same child chose to have their interviews combined into one. In the end, five separate parent interviews were conducted. Two interviews described daughters who are currently in high school but whose diagnoses are different and occurred at different points in life, with one being during infancy and the other in elementary school. One interview was done with both parents present. This interview described the family's recent experience with their child who was eight years old and in elementary school at the time of the interview and was diagnosed prior to entering junior kindergarten. Two separate interviews were conducted with members of one other couple, therefore representing two different views of the same family's experiences of their child's journey with cancer. Here the cancer survivor is their child who is now an adult who had been diagnosed prior to entering junior kindergarten and then relapsed again during elementary school.

Childhood cancer survivor interviews.

While the parents had already participated in the focus group and were therefore informed about the study, the survivors of childhood cancer had not. A separate assent

form as well as an age appropriate discussion of the study were provided for those children whose parents allowed them to participate in the interviews. These documents can be found in Appendix E and Appendix G. Interviews with the childhood cancer survivors were designed to obtain their own perspectives of their experiences at school. Personal interviews were chosen over focus groups with the childhood cancer survivors through the consideration of the possible age differences of the children who may participate. While the ages of the cancer survivors were unknown at the outset of the study, it turned out that they ranged from eight to twenty-eight years of age.

One major limitation of the use of interviews is that participants may not feel as comfortable speaking as they may in a group situation and the presence of the interviewer may bias the responses of the participants. The combination of focus groups and interviews were designed to address this limitation as much as possible. The combined information gathered from parents and childhood cancer survivors provided the opportunity for confirmation and extension of each other's accounts as they did in the study discussed by Closs (2000). The interviews were also designed to be as informal as possible, with the intention to provide the participants with a comfortable environment in which to speak about their feelings and experiences.

Of the four childhood cancer survivor contacts provided on the consent form, three cancer survivors participated in interviews. No reason was provided as to why the fourth survivor did not participate. One was the adult survivor who participated in the focus group. Another was a child who was diagnosed prior to kindergarten and was in elementary school at the time of the study. This is the same child who had both parents participate in the same interview. The other child interview was with a 16 year old

survivor who was in high school at the time of the study, but was diagnosed in elementary school. This child's parent also participated in an interview. Of these three participants, one was diagnosed with Leukemia and two were diagnosed with brain tumours.

Data Analysis and Interpretation

The focus group was video taped and the interviews were audiotaped. The data from the video and audio recordings were transcribed and analyzed using NVivo8 software. A within and cross case descriptive content analysis was conducted on the data gathered through the focus group and interviews. NVivo 8 qualitative analysis software was used to assist with data organization in the process of identifying themes. This process was completed through following Braun and Clarke's (2006) specific guidelines for thematic analysis, while also taking into consideration Creswell's (2003) generic processes for qualitative data analysis, and Fereday and Muir-Cochrane's (2006) hybrid approach of inductive and deductive thematic analysis.

As indicated by both Braun and Clarke (2006) and Creswell (2003), the initial stages of data analysis involve the researcher becoming familiar with the data. This is a vital stage in the analysis process as it ensures that the researcher is familiar with the depth of the content (Braun and Clarke, 2006). Creswell (2003) indicates that it is an opportunity for the researcher to gain a general sense of the data while reflecting on its meaning. This step was addressed initially through the process of transcribing the focus group and interviews. In addition, the audio tapes from the focus group and each interview were reviewed. Following these steps, each transcript was read and re-read to obtain a general impression of the data.

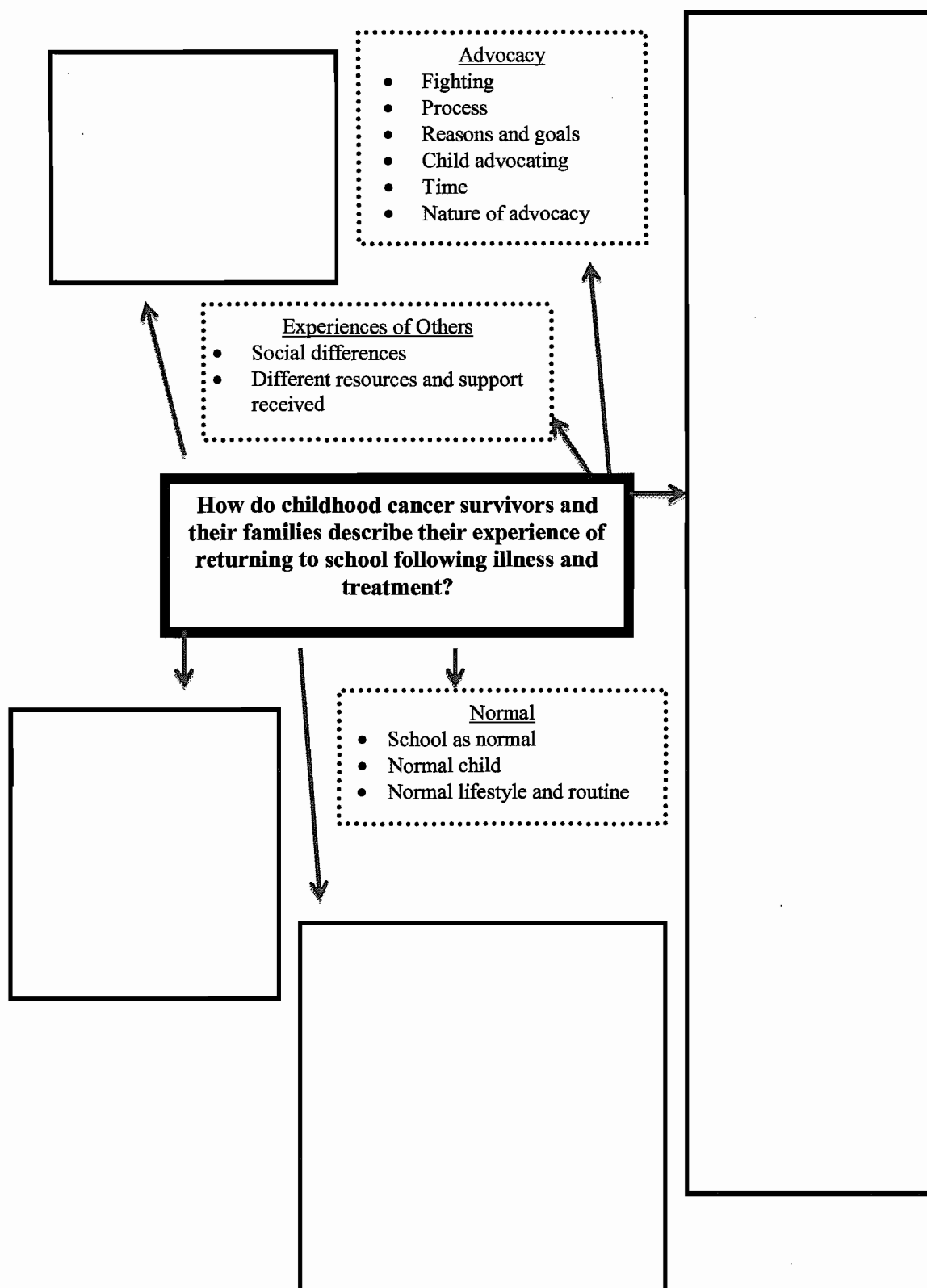
Following familiarization with the data, a preliminary deductive analysis was undertaken based on the four specific research questions that are a part of the broad research question of this project. In this phase, as indicated by Braun and Clarke (2006), the coding was deductive as it was approached with the specific questions as the basis for initial coding. The data were separated into four separate codes: Cognitive, Behavioural and Physical Changes; Peers and Social Concerns; Perceived Support and Siblings. This process was based on Creswell's (2003) recommendation to generate a small number of themes to organize the results under separate headings. This was also similar to Fereday and Muir-Cochrane's (2006) fourth stage of analysis in which the analysis of the text was guided by the preliminary codes, which were developed based on the research questions. For the purposes of this study, the analysis was guided by the existing research questions. All data gathered through the research initially fell within these four deductive themes.

Once the four research areas were coded deductively, each of the four themes was reviewed individually in order to gain a sense of the content. At this stage, notes and ideas for coding were recorded, as recommended by Braun and Clarke (2006). Once this was completed for each theme the process of an inductive analysis of each theme was conducted in order to further refine them. The codes and themes derived in this phase were data driven rather than theory or question driven as described in the earlier phase. This was completed through following Braun and Clarke's (2006) Phase 2 guidelines of generating initial codes, that suggest giving equal attention to each data item and searching for aspects in the data that may indicate repeating patterns or themes across the data set. Efforts were made to code for as many potential patterns as possible for the

within case analysis, as well as to code data extracts inclusively by including surrounding data in order to ensure that the context of each excerpt is not lost.

Once initial codes were created, Phase 3 of Braun and Clarke's (2006) thematic analysis guidelines, which involved searching for themes, began. Here, the various codes were sorted into potential themes. This was done by analyzing the codes and considering possible ways that they could combine to form overarching themes. Similar to the approach taken by Fereday and Muir-Cochrane (2006), codes were connected with each other in order to identify themes within the data across cases. During this stage it became apparent that several larger cross case themes emerged from within the deductive themes. These included Advocacy; The Idea of Being Normal; and The Experiences of Others. These themes were created as Tree Nodes in NVivo with data pertaining to the themes being coded within each. This is comparable to Fereday and Muir-Cochrane's (2006) method in which inductive codes were assigned to data that described a new theme. Following this step, Phase 2 of Braun and Clarke's (2006) guidelines was repeated for each of these four themes. At this point, Phase 3 was resumed for all of the major themes that were either inductively or deductively coded. The relationships among codes, themes and sub-themes were considered. In order to assist in organizing this information, a model was developed to include each theme and its subthemes. Braun and Clarke (2006) recommended using a visual representation as a tool to help sort the codes. This model can be seen in Figure 1.

Figure 1 – Data Analysis Model



Upon the initial organization of themes, Braun and Clarke's (2006) fourth phase, reviewing themes, began. In the process of reviewing the themes that had already been developed, efforts were made to ensure that each theme had enough data to support it. As suggested by Braun and Clarke (2006), "data within themes should cohere together meaningfully, while there should be clear and identifiable distinctions between themes" (p. 91). This phase involved two levels. In the first level, data extracts that were previously collated into themes were reviewed to ensure that they formed a coherent pattern. Coded excerpts that did not meet this standard were examined to determine next steps. These next steps included revising the theme by either separating the data extracts into separate themes, or moving the extract into a more suitable theme. Once this level was completed, the second level began. This level entailed considering the validity of each theme in relation to the data set. According to Braun and Clarke (2006), this phase involved reviewing the data set in order to confirm that the themes "worked" in relation to the data. Fereday and Muir-Cochrane (2006) also include a similar procedure in their sixth stage, which involves corroborating and legitimating coded themes. They recommended a revision of the interaction of the text, codes and themes before proceeding with an interpretation and depiction of the theme.

Once it had been confirmed that the themes fit together to provide an accurate representation of the data set, the fifth phase of Braun and Clarke's (2006) model commenced. Within this phase, each theme was reviewed and organized to form a consistent account of the data. A detailed analysis was conducted for each theme that identified how the data were important both within the theme and in relation to the overall story of the participants in relation to the research questions and objective of the

study. Data excerpts were chosen and included in the narrative based on the way in which they articulated the theme. Along with this, the sixth phase involving development of the narrative began. This phase of Braun and Clarke's (2006) model was similar to Creswell's (2003) fifth step of proceeding with representing the themes in the qualitative narrative. During this phase, efforts were taken to ensure the compliance with the recommendation that "Extracts need to be embedded within an analytic narrative that compellingly illustrates the story you are telling about your data" (Braun and Clarke, 2006). Fereday and Muir-Cochrane (2006) also highlight the importance of including raw data excerpts by saying that this helps to "ensure that data interpretation remains directly linked to the words of the participants" (p. 3). The description of each theme was written separately, focusing on the meaning of each theme and ensuring that the excerpts chosen were clear in expressing the ideas represented by the theme. Once each description was written, careful consideration was taken into how the themes interacted with each other in telling the story of the participants' experiences. Efforts were taken to arrange the descriptions in a way that clearly demonstrated how the themes interact with each other.

Results

The discussion that took place during the focus group and interviews involved various aspects of the cancer experience. Parents discussed the numerous concerns that they had throughout the process and the ways in which they worked to address them. Parents described their worries about their child's social interaction, including peers' responses to their appearance changes as well as limitations in the child's ability to participate in extracurricular activities. In addition to these, parents expressed concerns with their child's academics. Parents were concerned with the amount of school that their

child missed and expressed their worry about the potential side effects of their cancer treatment. One parent explained, “Now we’re hearing more and more about how you know, the chemotherapy can affect the memory and things like this, so you know, has that played a part?” (Participant 3) Some parents shared their concern about the whether treatment that their child had received would hinder their development and therefore have an impact on their academic abilities as well. Also contributing to parents’ concerns about their child’s academic achievement were the extensive absences from school, which resulted in children missing out on lessons and fundamental knowledge. These concerns were explored in greater detail and are described below. The experiences of the participants have been explored through focusing on the Cognitive, Behavioural and Physical Changes; Peers and Social Concerns; Perceived Support and Siblings. In addition to these, three emergent themes, including Advocacy; The Idea of Being Normal and The Experiences of Others, are also discussed.

Cognitive, Behavioural and Physical)

Cancer and its treatment can have a number of effects on an individual’s learning and development. The implications and challenges that the disease and treatment have on patients and survivors vary in form and are not the same among all children who are diagnosed with cancer. Of the many possible implications, this study aimed to explore whether children experienced any physical, behavioural or cognitive implications as a result of their illness and/or treatment. While the results did vary, one striking commonality among the data was the notion of children not wanting to appear to be different from their peers.

Not wanting to be different.

Whether the implications were a result of cognitive difficulties or physical changes, parents noted that children did not want these changes to be visible to their peers. One parent declared, "Being different is a huge thing" (Participant 3). Four participants comprised of three parents and one cancer survivor shared this feeling. With regard to cognitive difficulties, one participant who was removed from his/her classroom for special help stated, "I would have rather struggled myself, like inside the classroom as opposed to being segregated...I wouldn't say I had a lot of friends, but that kind of made it worse I guess" (Participant 10). This cancer survivor felt that from a social perspective, he/she would have preferred to lag behind his/her peers than be removed from the classroom, which differentiated him/her from the others. Two other parents mentioned the same response from their children who had the option to be removed from their classrooms for help with their academics.

Another factor identified by participants as contributing to children feeling different from their peers was the use of assistive devices. Two of the participants whose children experienced physical limitations as a result of their treatment revealed their children's refusal to use assistive devices. Although the devices were thought to be necessary by the parents, these children chose not to use them because of the attention that they drew from peers. When considering the ways in which children and their families experience these limitations, it is important to take into account the fact that these children do not want to appear as though they are different. One participant explained,

In his case, it took a long time to get – it's like anybody, take the time to understand that, "I have problems in this area and I need people to help me," and you know, a lot of the kids, they don't want to be identified as someone needing help. (Participant 2)

The desire to appear and feel like everyone else seemed to be a part of the way in which children and their families experienced the physical, behavioural and cognitive implications of cancer and its treatment.

Physical changes.

Participants explained that their children experienced a number of physical changes as a result of their illness and/or treatment. The physical changes that resulted from the cancer treatment took various forms. These included changes in appearance and abilities, variations in energy levels and increased hunger. All of these changes were noted by participants as side-effects of the cancer treatment that the children received. One participant explained that he/she felt exhausted at school from the time that he/she returned from treatment until the time the study was conducted, "My energy level at the end of the day, I'm just ready to take a nap and go to sleep. I find it really exhausting" (Participant 1a). This participant felt that the need to spend extra energy on focusing and concentrating throughout the day in order to compensate for the learning difficulties resulting from his/her treatment was what caused the fatigue. One parent described the fatigue experienced by his/her child who had hearing difficulties as a result of treatment. He/she explained that through the use of assistive devices, hearing impaired children pick up more information than necessary. This parent explained that after the child has had to discern which parts of information are important, "They come home from school and

they'd be exhausted because it's so much longer" (Participant 3). Another parent attributed his/her child's low stamina to the side effects of the drugs used in his/her treatment. Two of the childhood cancer survivors who participated in the study indicated that they had missed out on activities such as field trips and gym class as a result of this as well: "There were some field trips that I couldn't go on just because of my low energy level" (Participant 1a). This participant enjoyed the field trips that he/she was able to attend which suggests a sense of regret at having missed out on some other opportunities. Although he/she felt as though he/she was missing out on field trip opportunities, he/she shared that he/she did not mind having to sit out in gym class.

Drugs used in cancer treatment were also responsible for other physical changes in participants. Two families mentioned that their child gained weight as a result of steroids. The impact of the steroids was described by one parent by saying, "I mean, come on, athletes take the stuff to pump up their bodies, you know the stuff just – what it does, I mean I can't even tell you...the physical changes that you talk about, it's crazy stuff" (Participant 6). The child of this participant also experienced insatiable hunger when taking the steroids as a part of the treatment protocol. Physical changes also resulted in children feeling self-conscious. One parent confided, "She does have body image issues and things like that, but her friends are – and you know such a good support network" (Participant 3). This child's self-consciousness had not interfered with his/her peer relationships, however for other families, the changes in appearance were a major barrier to maintaining positive relationships with peers. One parent shared the reaction of his/her child's peers to the change his/her appearance by saying,

I know initially when she went back to school just for a visit to her home classroom, she had lost a lot of weight. She had an NG tube inserted in her nose, so of course that was something different for her classmates to see and a lot of them were like, they didn't know what to say because I guess they were still in shock because she'd gone from a real – you know, she wasn't a heavy child to begin with, but she just looked totally different. You could tell she was sick and they all were, you know, "What do I say to her? I don't want to say the wrong thing." (Participant 1)

The physical changes that this child had undergone alarmed peers, and they had difficulty relating to the child as a result of this.

Physical changes were not limited to appearance alone, but also resulted in changes in children's physical abilities. Two parents expressed their concerns regarding their child not being able to do the things that they had been able to do prior to their diagnosis. Examples of these things include participating in extra curricular activities and other physical activities such as dance and physical education. One parent expressed that he/she was less concerned about his/her child's academic progress in relation to his/her coping with the loss of abilities. This parent explained, "Two months before she fell sick, she was doing all of that, and now she wants to do it again, but she can't. So how do I explain to her, 'Hey you're, you know, you're different'" (Participant 17). The physical limitations and changes in abilities mentioned by parents included mobility changes as well as temporary changes associated with the control of body functions as a result of certain medications used. The effects of the medications and treatment protocols for

childhood cancer not only impact children physically, but they also have various implications for children's cognitive functioning.

Cognitive functioning.

All participants who contributed to the focus group or participated in an interview made some mention of cognitive impairments or academic struggles in one or more areas. These impairments were believed to be a result of the treatment protocol. As one parent stated, "They're realizing that all these chemo drugs and radiation and various things can really affect a child's learning ability" (Participant 2). These impairments and their resulting implications were discussed, as well as the ways in which they influenced the experiences of these families. Four of the participants mentioned that the cognitive issues that had resulted from the cancer treatment did not appear immediately, but rather, gradually over time. One parent explained,

But not everything shows up right away either. We had no issues to begin with, and like you were saying [pointing to another participant], as the years are going on I'm seeing it more than I ever did when she was first diagnosed. (Participant 13)

The impairments in cognitive functioning for a number of participants appeared to develop in conjunction with extensive absences, which ultimately resulted in participants experiencing academic issues. One parent expressed this by saying, "My main concern with the academics was the fact that he was missing still a fair amount of school" (Participant 2). This parent went on to say, "The fact was that earlier on in his treatment he had some cranial radiation and this is when it starts to show up" (Participant 2). Parents acknowledged that the gaps in their child's learning were a result of their

absences, making note of them missing out on fundamentals when absent in the early years of school and missing new material taught as children move from primary to junior divisions in school. The cognitive impairments that children experienced included challenges in memory functioning as well as difficulties in areas relating to organization and math skills. These impairments were often manifested in the school setting, resulting in the children experiencing academic issues.

Academic issues related to cognitive functioning.

Many of the issues that resulted from the cancer treatment became evident in the school setting and created academic challenges for the children. Four parents noted that their child experienced memory problems that were manifested in the school setting. One parent described his/her child's desire to pursue a career that would involve post secondary education. When referring to this career choice, the parent said, "Which is going to be a tough field for him because he suffers memory loss, short term and longer term" (Participant 8). This parent acknowledged the battle that his/her child would have to undergo in order to achieve this goal. Another parent linked his/her child's memory loss to difficulties in thought processing as well. This parent shared that his/her child often repeated statements in a span of five or ten minutes, not remembering that he/she had already shared the information. This parent also found that his/her child often misinterpreted information that was said. One of the cancer survivors who participated in the study described how difficulties with thought processing were manifested in the classroom by saying, "I sometimes do have trouble collecting my thoughts. Like I'll raise my hand but it'll take me a minute to say what I want to say" (Participant 1a). This participant felt that having teachers employ strategies and accommodations that would

help to break down the amount of material being presented would help to address these difficulties.

Breaking down course content and expectations was also listed as a solution for difficulties with organization and multi-tasking. Two of the children represented in the study appeared to have trouble when it came to these tasks. One participant shared, “So basically I had to focus on one thing rather than doing a bunch of other things, or two or three things at the same time, whether it be activities or somebody explaining something to me” (Participant 10). This type of impediment appeared to have an effect on the child’s academic functioning when it came time to break down large projects and manage multiple projects that were occurring simultaneously in various classes.

The cognitive impairments related to the cancer treatment appeared most often to have a negative effect on children’s performance in math and language. Four of the children represented in the study were said to have challenges in language classes. Two of the children were removed from their regular class in order to receive extra help and/or received tutoring in language, focusing on reading, spelling and editing. Similar to language, four children were said to have trouble in math and this was the area that most parents identified as being problematic for their children. When evaluating their child’s academic abilities and challenges, one parent stated, “Math is her biggest struggle I think” (Participant 6). One child was removed from his/her regular class for remedial work in math and one child had a tutor in order to help him/her get through the required math courses in high school. Contrary to the majority of participants listing math as their major academic challenge, one child enjoyed math. This child stated that math class was one of his/her favourite classes because, “It’s one of my best marks and I can understand

math” (Participant 1a). For another child participant, although his/her parents indicated that math was the biggest challenge, the child felt that it was becoming easier. This child’s parent had suggested that this may be a result of the remedial work and tutoring that were being provided.

When discussing the children’s academic challenges, frustration and stress were mentioned as the result of these struggles for five of the children represented in the study. The frustration was mentioned as a result of having difficulties in certain subjects. When asked if they thought that his/her child’s academic needs influenced how he/she felt about school, one parent answered, “Yes it does. Yes, because I think she gets frustrated because sometimes it’s like a whole bunch of information at once and like, she has four classes” (Participant 1). The increasing difficulty in course content, along with juggling multiple classes, was also cited as a source of frustration for another child in the study. A second source of frustration relating to cognitive and academic challenges was being pulled out of class for remedial work. In both of these cases, the frustration was related to the child not wanting to be different from his/her peers. All three of the cancer survivors who participated in the study indicated that they were concerned about how they did in school. One participant shared,

I do worry a lot about how I do in high school, in like school. I do get good marks but I worry a lot and I really, really, really try hard to keep my marks as high as they are. Like I struggle to keep my marks where they are. They are good grades but I work really, really hard to keep them. (Participant 1a)

For this participant, as well as another cancer survivor, there was a concern with their performance in school as well as their grades. They appeared to be worried that they were

not doing well. The other survivor who participated in the study shared a concern about doing well at school, however this concern was more geared towards having options for career paths in the future. He/she realized that in order to graduate and get a job, the work had to get done. Despite the academic challenges that children faced, they appeared to be interested in their own academic achievement and worked to ensure that they succeeded.

Resilience and striving to achieve.

The cognitive impairments that resulted from treatment protocols created difficulties for the children in this study. Despite these challenges, it is important to note that many of the children were resilient with regards to these academic challenges, and therefore were able to succeed. Four parents and all three of the cancer survivors who participated in the study described the extreme effort that the children put forth when it came to their schoolwork. One participant described this situation by saying,

I can't remember that he ever won kind of a best math award or a best science award or something like that. He won awards for effort, most improved, you know, that sort of thing, but he definitely was lagging behind and you know, he realized that he had to work much harder than, you know, even his brother or sister, you know, or obviously his own peers. (Participant 5)

As a result of this effort, as well as tutoring, remedial work and varied accommodations, many of the children appeared to improve in areas in which they had struggled, and some of them even excelled in certain subjects. One of the cancer survivors acknowledged his/her struggles and improvements by saying, "Like math is much more easier for me now, and language and science" (Participant 6a). Despite having trouble in these subjects

in the past, this participant was able to bring him/herself to the same level as his/her peers, which was a source of understandable pride.

Behavioural changes and challenges.

Cognitive challenges were not the only challenges that participants reported as being associated with treatment side-effects. The treatments can result in behavioural changes, which may also appear due to the realities of experiencing cancer and reintegrating into school. Only a few of the parents who participated in the study spoke about their child's behaviour changing either during or following treatment. The findings were mixed, with some parents identifying clear changes and some being unable to detect changes. One parent, who admitted that changes were clear from the beginning, stated,

Pre-treatment she was a bubbly outgoing girl, not afraid to take risks. You know, she was friends with everybody and always kid of – she was very social. And now, of course she's going through a difficult age too, but she's very sensitive, very touchy. She's not as much of a risk taker as she once was. (Participant 1)

In contrast to this striking change, another parent revealed his/her difficulty in identifying a change in behaviour. When asked if his/her child's behaviour had changed, this parent responded by saying,

Oh yeah, that's a tough question because you never know what he would have been like if he didn't go through these periods...you don't know what he would have been like obviously without going through this experience because you can't pull back and say this didn't happen. (Participant 5)

This parent was referring to overall personality traits and changes, rather than specific school related behavioural challenges.

When considering school related behaviour, again, the results appeared to be mixed. One family indicated, “He never exhibited behavioural problems academically” (Participant 2), despite being frustrated with academic challenges. Contrary to this family’s experience, another parent felt that his/her situation was the opposite and stated, “I had her IEP changed from academic to behaviour because she was having considerable amounts of difficulty expressing that she was having difficulty” (Participant 6). While talking with this parent, it appeared that the difficulties were a result of changes in the child’s abilities, both academic and physical. This parent also acknowledged a change in his/her child’s behaviour while on treatment by saying, “She was also taking steroids, which has a huge, huge, impact on behaviour in itself” (Participant 6). Overall, it appeared that the effect that treatment protocols and the cancer experience had on children’s behaviour varied, as did the effects on physical, and cognitive findings. However, the presence of cognitive difficulties was much more consistent than that of behavioural or physical changes.

Social and Peer Related Aspects of the Cancer Experience

Peer relationships appeared to be an important source of support for children who have cancer. For many of the participants of this study, the decision for children to return to school was based on parents’ desire for them to be able to interact with their peers. One parent described this by saying, “I more or less wanted her to be able to hang out with her friends again and you know, have that connection, because she was missing that when we moved home” (Participant 1). For two other families who shared this wish, it was clear that the opportunities for socializing with peers were more important than their

concern for academics at the time of deciding whether or not their child was ready to return to school.

The decision to return to school created a number of concerns for both children and parents. Participants often declared that their biggest concerns were related to peer reactions and support. One parent shared, "The biggest concern I remember I had was his peers supporting him, because you know, peers can be nasty or supportive in terms of that" (Participant 5). Four of the participants who shared their worries about their child returning to school indicated that their child's appearance and how peers would respond to them was a key source of their concern: "Yeah, I think we were concerned, or as a parent I was probably more concerned about the appearance aspect than he was...but I think it was the appearance aspect and how he would be treated by his peers" (Participant 11). These concerns left both parents and children feeling nervous about the return to school. This nervousness was cited for both the initial return to school following their diagnosis, as well as when children returned to school following prolonged absences as a result of their illness. One parent shared his/her child's experience by saying, "He wasn't doing that well, his immune system was very low so, I didn't send him for a few weeks. Now he's, like he's nervous then and the kids aren't as supportive" (Participant 12). One of the cancer survivors who participated in the study also shared that he/she felt nervous about the return to school and was worried about being teased by classmates.

Whether or not the children had concerns about peers varied. When asked if there were any concerns expressed about peer rejection or other peer related issues, one participant replied,

Not that I can even remember...for him it was just like if there was a problem with somebody, he just kind of like, "Fine, if that's the way you want to be. You know, I have enough going on in my life, I'm just going to play with other people". (Participant 2)

Two other children were also reported to not be overly concerned with peer issues. In contrast to this, one participant responded to the question above by saying,

Well yeah, like she doesn't belong...she spent a lot of time at home not feeling well, but I think more if it was that she didn't want to be at school because of the way her peers treated her and she didn't know how to overcome that I guess.

(Participant 1)

One parent shared that his/her child's concerns were related to not being able to fit in: "She had a really hard time in grade one fitting in socially and emotionally because she didn't know how. She missed so much of it that she didn't know how" (Participant 6). Similar to this, two of the cancer survivors who participated in the study indicated that they did not have many friends at school. Both of these participants described how they did have a few friends that they considered supportive, however, they did not appear to have a large social network.

Nature of peer relationships.

While many of the participants in the study indicated that they chose to have their children begin or return to school for socialization purposes, not all of these relationships remained the same. Participants explained that there were changes in the nature of their child's relationships with their peers. Four of the parent participants and one of the cancer survivors who participated in the study suggested that the degree of support received

from peers had changed. One parent described this change by saying, “Everybody called while she was sick at first, and now it’s like a couple of friends who are sticking by her and that’s it. The rest don’t come – don’t call anymore” (Participant 16). Another parent shared a similar story and described his/her child’s friends as being “All right there, you know, calling the house constantly and calling the hospital,” but then went on to say that, “Since we’ve, you know, have gotten past that now, his friends have all kind of just left” (Participant 8). Although this paints a dim picture of the stability of friendships following a cancer diagnosis and treatment, two participants indicated that more positive friendships had developed.

The termination of some friendships along with the development of others was described by one parent as being a choice of the cancer survivor, and not just the result of the reactions of peers. It was noted by five participants that children who have experienced cancer were thought to be more mature than their peers. One participant described this idea by saying,

I know my daughter was a little older when she got sick and she does have some really devoted, I’ll say, good friends, but because they’ve gone through this, they realize who are their true friends and who aren’t their true friends and who they have no time for...because they’ve gone through so much they grow up so quickly that they’re more mature than some of their own peers at that age, that they do tend to sometimes pick new friends that they would like to model or have the same views and values that they do, and not always the ones that they were going to school with then, when they were diagnosed. (Participant 13)

Other parents described the difference in maturity levels by saying that their child was seeing things differently, not understanding the little things that bothered their peers and being able to take on bigger challenges than same age peers might be able to do.

The different maturity levels and interests of cancer survivors and their peers did not seem to have an effect on friendships outside of school. A number of the children in the study were said to have positive support networks outside of school. One parent shared that his/her child's closest friends were from a youth group. He/she described these friendships by saying, "She's in a youth group, most of them are older than her, but she's very close to them. She seems to relate very well with them" (Participant 1).

Although relating to same age peers in the school setting may have been a challenge, it appeared that children have found other sources from which they were able to develop meaningful friendships. Two other families mentioned that specialized camps, organized for cancer survivors and their families, were a source of positive friendships where the children were able to relate to others who had similar experiences. In addition to these, sports teams were also reported as a source of a supportive network of friends for one child who was represented in the study. Although some children experienced a change in their relationships with their peers, the majority of these changes were positive, with children receiving support from their peers.

Supportive peer relationships.

In addition to discussing the nature of peer relationships, the focus group and interviews explored the ways in which peers communicated their support. When asked whether they felt that their child had supportive friends, six of the parents and two of the

cancer survivors who participated in the study indicated that they were happy with the level of peer support that was received. One parent shared,

When they learn, they become even more supportive. She has a phenomenal network of really good close friends and that who are really supportive...there are some things that I can see with peers that so many of them have been so supportive of her. (Participant 3)

Many of the participants described this support by sharing their knowledge of special gestures that were made by their child's peers. Three of the parents and one of the cancer survivors who participated in the study mentioned the joy that was experienced when they received cards and letters from classmates. One participant explained,

When I was in the hospital, a bunch of kids, like as a class, sent me letters and I got a big card from the school. A bunch of people signed it. People from the church, people from the school, and when I got those cards, it made me feel so much, like so good. (Participant 1a)

Other supportive gestures that were shared included gifts, surprise parties and visits to the hospital by friends. One parent shared a story of a friend using his/her cake decorating skills to help prepare for a youth group party. Another parent indicated that in addition to such gestures, what was most important to his/her child was that, "He was just one of the guys. He was one of the group" (Participant 2). Here, the peer support was sensed through being included in the peer group.

For some families, peers were seen as being supportive by looking out for the child who had cancer and acting as caregivers. When describing one supportive friend, one participant shared, "She sticks up for [named child] when the other peers were

picking on her in their class” (Participant 1). Another parent revealed that his/her child had a friend who would often help the child and find a teacher when he/she was hurt.

A number of the participants in the study explained that they found it beneficial to have an existing peer group prior to the cancer diagnosis. One participant shared his/her experience by saying,

Our experience was because [names child] was sick as a child and went to school sick, but then he was diagnosed later on, if anything, his peer group, and fortunately we were with the same group all the way along through all of his elementary school years, they were the same kids. So, if anything, they were very supportive and very protective of him. Even to the point of reminding him to take his medications and things like that. So, so we were very fortunate. (Participant 11)

Another family who also spoke of the benefits of having the same peer group referred to this as a source of social stability during the cancer experience. However, having the same group of peers before and during the cancer experience did not appear to be beneficial for all families. When talking about his/her child being bullied and teased by peers, one parent shared,

Yeah, I think it was related to the treatment because like most of the students in her elementary school had been with her since SK, senior kindergarten, so they knew her before and they see her after. I mean, she was a different person...so as a result of that, like you know, her peers didn't relate to her and she couldn't relate to them. (Participant 1)

While most families shared that having the same peers throughout the experience increased the sense of support that was felt by the child and family, the experience for this family was the opposite of that. For this family, the peers were not able to understand the experience and the resulting changes in their friend, and were therefore less supportive than the peers of other participants.

Non-supportive peer relationships.

Although many of the peer interactions described by participants were supportive, participants in the study also described examples of incidents in which they felt that peers were not as supportive as they would have liked. Four of the families who participated in the study mentioned incidents of teasing and bullying from peers. Two of the participants mentioned that the teasing and bullying were a result of changes in appearance. When asked about his/her worst experience at school, one participant shared, “Uh, probably when other kids were making fun of me that I didn’t have any hair and they didn’t like me anymore” (Participant 6a). When later asked how he/she solved that problem, the participant responded by saying, “Um, my hair started to grow back and I got happier and stuff and that got rid of the problem and people started to be my friend” (Participant 6a). One other participant also commented on the fact that his/her child was teased as a result of his/her hair loss, and that the teasing ceased once the hair had grown back. Another family shared examples of bullying, both online and in school. One participant revealed, “Like nobody talked to me once I got back from – like once I got back to elementary school. People started making fun of me, started spreading rumours” (Participant 1a).

Although not all participants shared examples of bullying, one parent said that his/her child felt as though he/she was a burden on his/her peers as a result of needing

extra assistance. This parent said, “The only thing I’ve noticed with her is a couple times that she’s actually physically said, ‘I feel like I’m aggravating my friends, I feel like I’m making them mad at me’” (Participant 17). This parent had asked the child why he/she felt that way, but the child was not able to provide specific examples. This parent stated that his/her child had only two close friends following his/her cancer treatment. All three of the cancer survivors who participated in the study also stated that they had only a few close friends after their cancer experience. Two participants indicated having only one close friend who was considered supportive, while two other participants stated that they had two close friends. One participant attributed his/her lack of friends to the fact that he/she was taken out of the classroom for remedial work. This participant shared his/her experience by saying,

I remember myself, I was pulled out of spelling, definitely. I’m not saying I wasn’t good at it, but I – it’s not something I wanted to be pulled out of. I would have rather have struggled myself, like inside the classroom, as opposed to being segregated, because once I moved to the new school there was – I wouldn’t say I had a lot of friends, but that kind of made it worse I guess. (Participant 10)

This participant expressed that by being segregated from peers for the purpose of extra help, he/she found it difficult to make friends and to have peers understand his/her situation. When asked for suggestions or recommendations for other children who are diagnosed with cancer, this participant suggested that someone explain the child’s situation to the class so that peers could better understand and accept him/her. This participant also stated, “So that they can understand. Not so that they can use that to ridicule people because they have cancer or because they have a learning disability

because of having cancer” (Participant 10). It was evident that having peers be aware of the child’s circumstances was seen as important for having them be more accepting and supportive of the child.

Peer knowledge and education relating to cancer.

The importance of educating peers about cancer and about each child’s specific circumstances was significant to participants because it was seen as a way to increase acceptance. Similar to the concerns mentioned above regarding being ridiculed about having cancer and the associated learning difficulties, two participants spoke of misconceptions that peers had regarding their condition. In reference to overhearing peers talk about his/her cancer, one participant explained, “They kind of messed it up, so they changed some parts in there that I’ve been telling them” (Participant 6a). When asked for specific examples of the things that were mixed up, this participant replied, “Hmm, maybe when they said that [participant’s name]’s hair fell out and then like after one day it grew back. And I actually told them that like after a long time it grew back” (Participant 6a). One other participant shared examples of times when peers made jokes about not wanting to catch cancer from him/her child. In response to these and other misconceptions, when asked what they thought that peers should learn about cancer, one participant suggested, “Well kids who have cancer are the same as everybody else, just we have cancer now. Like we’re still the same person on the inside pretty much. And you know, you’re not going to catch cancer” (Participant 1a). In addition to misconceptions, two of the cancer survivors who participated in the study and one of the parents spoke of peers asking a lot of questions. Looking back on his/her experiences of being asked questions by his/her peers, one participant expressed the concern that, “I don’t know if I

would have been able to explain any of it at that age” (Participant 10). Another participant recalled not minding questions at appropriate times, but disliked being approached by a rush of peers crowding around him/her and asking questions.

Participants’ views on whether or not children enjoyed talking to their peers about cancer varied. Two parent participants revealed that their child spoke at their high schools about their cancer experience. Both of these events were in relation to other public awareness campaigns. According to their parents, the children shared their experiences as a way to help with the initiatives that were taking place. In contrast to these examples, all three of the cancer survivors who participated in the study revealed that they did not often talk about the cancer experience with their peers. One participant said, “I don’t know if they actually knew that I had cancer in the second school to be honest...I never brought it up” (Participant 10). Another participant who had moved to a new school also shared that that not everybody at the new school knew about his/her illness. Even within the same school setting, when speaking about talking to a good friend about cancer, this participant said, “She knows, just that I had cancer, because people started to come to the school talking about it, but I don’t talk about it” (Participant 6a). For this participant, it was fine to have a presentation done for his/her classmates, however he/she chose not to discuss his/her cancer as a regular part of conversation with peers.

Parents reported that it was important to educate children about cancer. One participant stated,

Well again, I think they probably could be more informed...because you know, the lack of knowledge people – ignorance is bliss, so I say. If they don’t know,

then, like they can't accept. So if they know about it, they're more able to, I guess not be so afraid of it, would be the right way of saying it. (Participant 1)

Having a presentation done to educate peers about cancer was regarded by the majority of the participants as an effective way of increasing peer support and understanding. Simply stated, "Because we had gone into the classroom and talked to the kids and shown the video, and with his hair loss and various things, they were just accepting" (Participant 2). In this case, the child had participated in the presentation by describing his/her situation and explaining various facts to his/her peers. While most families found this to be beneficial, one family realized that it was not enough to solve all issues with peers. As stated by one participant, "It helped, but I think they were still stuck up in their own ways and you know, didn't like me" (Participant 1a). For this child, peers seemed open to learning about his/her illness initially, yet over time they became less supportive. When a follow-up presentation was done in an attempt to increase acceptance and peer support, peers seemed uninterested in learning about his/her circumstances. Their behaviour towards this child had become very negative, yet the information and presentation did not appear to help solve this problem. In spite of this unpleasant experience, participants agreed that educating peers about cancer and about their child's specific needs was the key factor in ensuring that the peers were supportive and accepted the child who had cancer.

Perceived Support

Infrastructure

In discussing the experience of returning to school following their child's diagnosis and/or treatment, families discussed issues related to the infrastructure in

schools that was necessary to support their child. Included in these discussions were descriptions of effective supports and supports that were not available as well the processes families used to access or advocate for supports

Meetings with school personnel.

When discussing families' perceived access to support services for their children, six of the parents who participated in the study mentioned attending meetings with school staff in order to communicate their child's needs and/or arrange for educational support. The school staff that participated in these meetings varied, with some including board staff, principals and teachers, and some with just teachers. When referring to the success of his/her parent's meetings at the school, one participant shared, "She has more success talking to the teachers individually than she does talking to the special needs teacher" (Participant 1a). Participants representing three different families specifically mentioned having regular meetings with their child's individual teachers. One parent shared his/her reasoning by saying,

I try and meet with the teachers like when they have their mid-term thing or whatever, but sometimes I have tried to meet them before that period but once they – because I realize that they don't always read the IEP so they don't always know that [names daughter] had a brain tumour or that she has all the other problems. But I found that once I had spoken to them myself and let them know, they seem a little more understanding and realized that if she's saying she needs this, then she's not just saying it because she doesn't want to do it. But again, it's like you have to keep reminding them. (Participant 1)

One parent illustrated the importance of meeting with teachers by sharing his/her experience when he/she was unable to do so. Reflecting on that event, this participant stated, “It was a learning thing for us, knowing that I had to sit down with each teacher each semester and give them a heads up of what needed to be done” (Participant 2). Both of these families chose to have regular meetings with their child’s teachers as a way to ensure that their child’s needs were met.

Parents who discussed meeting with teachers spoke of countless meetings that they had with school staff. One parent shared his/her experience of these meetings by saying,

Every year we have a meeting with the principal or the teachers. Every year we’ve had a meeting with the special ed – one of the special ed teachers and the teachers and stuff like that and I think that’s, you know, being proactive and a lot of that necessarily didn’t come from us. It came from that one teacher. (Participant 3)

For this participant, the meetings were a result of a suggestion from a previous teacher as a way to ensure that the necessary supports were put in place. Three participants made reference to having the help of either a parent advocate from their support group or other health care professionals who attended the school meetings with them in order to ensure that the needed resources were put in place for their child. One parent shared, “I basically went in and I had [parent advocate], I had the nurse, I had the physiotherapist – no, the nurse didn’t come, but I had our case worker from CCAC was there. Basically, whoever I could take in” (Participant 6). Parents referred to the help that was received as a way of convincing the school staff of the need for the resources and supports that they were petitioning for. Parents often had to have multiple meetings with school officials in order

to secure the resources that they felt their child required. Two other parents who participated in the study also spoke of their experiences of acting as advocates for other families at school meetings. Both of these participants shared stories of meetings that appeared successful, but later proved to be ineffective in the long run. As one parent explained, “The professionals would come in, maybe a nurse would come in or a social worker and they get that feeling and then a couple weeks later things don’t work out” (Participant 2). This parent was describing the frustration that parents experienced in having to have repeated meetings in order to get what their child needed.

Two families who participated in the study found that communicating with teachers and receiving support was more difficult in high school. One parent stated, “It’s harder at the high school level because you deal with four in the first and four in the second. So you’ve got eight teachers that you have to deal with in a school year” (Participant 8). One other parent shared his/her belief that support was harder to get in high school as a result of the larger class sizes. According to these families, it was easier to receive adequate support in elementary school than it was in high school and university. Overall, parents highlighted the importance of having a teacher be aware of their child’s circumstances, while also making it clear that they felt that the responsibility was left to them to provide the teachers with the necessary information. Participants felt that without these meetings, their child would not receive the academic support that they required.

Funding and coordinating support.

When discussing the accessibility and implementation of various supports and resources, participants referred to funding and budget allocation as a barrier to receiving

support. After repeatedly petitioning for support, one family was told that they could not receive all of the required supports for their child and that they would have to choose between certain supports such as having an Educational Assistant (EA) in place or receiving home schooling. One parent explained,

It was, “Oh, you can either have this, or you can have this. You can’t have both,” so you can’t have home instruction and have an EA at the same time. You can’t have both, you have to choose basically – it’s like, “What? I need both.”

(Participant 6)

The child was not able to have an EA in place because he/she was missing a large amount of school. In this instance, the family chose to have home support, however they were frustrated with the time that it took to have that resource put in place. For a number of families, the allocation of school supports and resources was perceived to be dependent on school budgets and funding. One parent shared his/her experience with funding cuts by saying,

Our school board just cut the EA budget...we just lost our EA that we had before Christmas and it just destroyed [names child], it destroyed her, changed – the change in my daughter, it’s immense...the EA, the budget, it’s just horrible now that the school board cut it. (Participant 17)

While this was a particularly unique situation, another parent shared his/her views of the challenges that families were faced with by saying, “Unfortunately, with reality, we’re into a cutback mode with the economy and that and if they start cutting back resources, it’s not going to be any better. The challenges are going to be even worse” (Participant 5). Parents were faced with the challenge of consistently having to advocate for their child in

order to ensure that resources and support systems were put in place for them. Parents were concerned that economic changes and budget cutbacks would intensify their existing challenges since budgets and funding were already perceived as barriers to receiving necessary resources.

Measures taken to obtain support.

When discussing support services for their child and the challenges that they experienced, participants described the ways in which they sought out support. One common means of attaining the necessary support services for their child was having reports from either the child's Oncologists or from Psychologists. The reports attested to the academic challenges that the child was faced with. Five participants indicated that support for their child improved as a result of having these reports. One parent had a neuropsychological assessment for his/her child and explained the value of this type of assessment by saying,

That documentation is so important in dealing with the school system, because if they have that kind of assessment then it's written down to say, "Okay, these are the challenges," whether they have memory loss or information processing, or fine motor problems. By having it documented, then that piece of paper, going into the schools, when you're sitting down and doing your child's individual education plan, is going to be very, very helpful. (Participant 2)

Other parents who participated in the study also spoke of using these reports and assessments in the development of their child's IEP. One parent spoke of requesting a letter from his/her child's oncologist to be used in conjunction with a university application. The report asked that a particular grade not be included when calculating the

student's average since the low grade was due to the effects that the disease and treatment had on the child's academic performance. This parent commented that his/her child was admitted into his/her chosen university program, likely as a result of having this letter.

While the reports were effective for these families, two other participants shared their frustration with the fact that their reports did not necessarily result in their child receiving the support that they required. When asked if his/her child received academic support, one parent answered, "Not a whole lot no matter how much we tried to fight for that. Even with the psych test that we had and the recommendations" (Participant 1). Another parent shared his/her frustration with the process of sharing the reports with the school by saying, "They have to be worded – like they phoned me from school too for [names son] and said it has to be certain words, so I have to go to [hospital] to change, you know, talk to them, if they would change the wording" (Participant 12). For this family, specific vocabulary had to be used in the report in order for the school system to recognize his/her child's needs and provide the required resources. Overall, parents believed that having documentation that could attest to their child's needs was effective in securing support for their child, however it did not appear to be successful for all participants.

Identification.

Similar to the need for specific wording in a psychological report, there are also specific categories of exceptionalities that are recognized within the school system. One of the concerns that a number of parents spoke of was the fact that childhood cancer does not fit directly into one of the categories of exceptionality defined by the Ministry of

Education. This made it more challenging for parents to petition for their child to receive the support that they required. One parent shared his/her frustration by saying,

The school only recognizes certain things right, so a lot of the symptoms and things like that that she would experience on a temporary basis – because they were temporary or they didn't fit a criteria of a single diagnosis, so therefore they wouldn't commit resources. (Participant 7)

This parent felt that there should be a standardized procedure for recognizing needs and allocating resources for children who have cancer. Another parent shared his/her frustration with the categories of exceptionality by saying, "But there's nothing cut in stone that our kids can be pigeon holed into and that's probably the biggest issue that we've all had. You know, they have problems, but where can I pigeon hole them?" (Participant 3) By not falling into one specific category, families were left to work extra hard in order to have their child's needs acknowledged and met.

As explained by three participants, one of the biggest issues that families whose children have cancer faced was working to have children who have cancer recognized under the category of Medically Fragile. One parent explained,

We have written to the Ministry and I know [another participant] brought it up to his school board as a category of considered to be medically fragile. Which is, it's really a category we would like because that's what our children are when they're going through treatment, and it – I mean, yes, they might have other issues. They might end up with memory issues or learning or vision or hearing or physical, but at least that's part of it. So I think we have to kind of push at the really high level to try to get another category in there so that our kids are going to be identified.

Then you're going to be guaranteed that you're going to get that support all the way through. Only what you need, but at least knowing that you can access it.

(Participant 2)

While these participants acknowledged that not all parents wished to have their child identified and labeled with a specific exceptionality, they felt that by being identified within one of the categories of exceptionality, their child would be guaranteed to receive support.

Educational hierarchy.

When speaking to participants about their efforts to obtain support for their child, four participants made reference to the hierarchy within the education system. Two participants mentioned going to a higher level to ensure that their child was being supported. One of these parents made reference to the principal being at the top of the hierarchy within the school by saying, "They were kind of up there for the general stuff...so it was so important to go to the top to sort of, you know, 'This is what we're dealing with,' and from there, working with the individual teacher" (Participant 2). This participant also noted that in the event of having an issue with a teacher, he/she could turn to the principal, who is at a higher level, to have that issue solved. Another participant referred to the hierarchy by mentioning that when he/she encountered a principal who was unwilling to accommodate a child who had cancer, he/she went to the school board in search of support.

While these families were turning to a higher level to seek out support, one participant had an experience where the higher level was being blamed for a lack of support. This parent explained,

Or you can get somebody who's very stubborn and says, "Well I'm being told by upper that you know we can't do this," which is what we ran into with the principal at [school] and [names child] never did get the home schooling when he needed it. (Participant 8)

This parent was unsure of how to proceed once the principal had stated that the decisions were passed down from a higher level. Two parents felt as though it was the "higher levels" within the hierarchy that acted as barriers or challenges when it came to obtaining support for their child. The mix in perceptions indicates a degree of inconsistency within the school system in providing support for these children. With that being said, it is also important to keep in mind the uniqueness of each family's situation, as some children's needs would have been much greater than others, requiring differing degrees of support between families.

Hospital teachers.

Support services required and received by families varied greatly. One of the many different forms of support described by participants included hospital teachers. Only one participant acknowledged having educational support while his/her child was in the hospital. This participant described the support by saying,

Because most of his treatment was outpatient, we had an arrangement that the teacher that was in the school would meet us in clinic and would work on some stuff with him. Like the school would – even if he had, if he was supposed to be having a test that day, the teacher at the school would do it at the hospital while we were waiting. (Participant 2)

For this family, the support and teaching were arranged by the school rather than provided by the hospital. Two participants specifically stated that they did not receive any teaching or educational support in the hospital and no other participants made reference to having hospital teachers. The lack of mention of having hospital teachers, as well as the lack of support that families received from hospital teachers indicates that this form of support was not available to many participants. It is also possible that participants did not view this support as necessary for their child.

Tutors.

In addition to mentioning hospital teachers, parents also listed tutoring outside of school as a source of support to assist their child. Three participants, representing two different families, spoke of having tutors work with their child. One family acknowledged that they had their tutoring funded by the school board. This parent stated, “I was fortunate, personally, to advocate enough to have the school board keep paying for tutoring even after he came off treatment” (Participant 2). This tutoring began as a part of the child’s homeschooling while he/she was on treatment, yet the family was able to continue having that as a support throughout the rest of elementary and high school.

One participant spoke of using private tutoring to help his/her child: “We spent extra money and we used outside resources like Oxford Learning Centre to bring her to where she needs to be” (Participant 6). Although his/her child was being supported at school through various accommodations and special help, he/she felt that the private tutoring was helpful in order to have his/her child achieve at the appropriate academic level. The increasing degree of academic difficulty also caused the family that did receive

school funded tutoring to hire a private tutor for a short time in order to provide their child with extra assistance.

The participants whose children received both private and school funded tutoring found that their child benefited from the extra assistance. One parent stated, “I think in some ways that he knew that he needed that to manage as well as he was doing, and he knew that it was making a difference for him” (Participant 2). Tutoring was believed to increase the confidence of both of the children who had received it and parents felt that having a tutor, rather than the parents themselves helping, was beneficial. Although only two families received a tutor and found that it was a valuable support, two of the cancer survivors who participated in the study indicated that they would like to have had a tutor to help them as well. Despite having wanted the help of a tutor, they did not receive one and were not aware of the reasons why this was denied. While some participants did not have access to a tutor, those who did indicated the value and benefit that they felt were provided through having this resource.

Home instruction.

Along with tutors, seven participants mentioned having home instruction while their child was involved in treatment. One of the major challenges described by participants was the number of conditions that had to be met in order for a child to qualify for this service. Three participants explained that eligibility for home instruction was based on the amount of time that a child was absent from school. A child had to be absent for a set number of consecutive days in order to qualify for home schooling. This created a challenge for families when it came to both initiating and continuing home instruction. One parent summed up his/her perceived challenges by saying,

The illness and when they miss school is very sporadic and then there's a process to getting the education started, so once you get the home schooling started, they're usually back in school already, so there was, there was that problem as well. And then it was whether they would find somebody that could do it and if there was somebody available then you might get it. (Participant 11)

One parent mentioned advocating in order to have home instruction in place for the entire time that a child is involved in treatment rather than the current standard where it is usually only provided for the initial time when the child is in the hospital and absent from school. Another parent described the inconsistency in home schooling by saying, "If a kid goes back to school, the home schooling stops, even for one day, the home schooling stops" (Participant 3). In this case, the parent had mentioned speaking to a principal who had agreed to work around the system and mark the child as absent, even when he/she attended school. This was done to ensure that the child's home schooling could continue even if he/she was periodically able to return to school.

Once the home schooling was put into place, views on its benefits varied among participants. Two participants indicated that it was very helpful for their child, however they also stated that they needed more. One parent stated,

By the time – the two times it was put in place – it was put in place by maybe March, so by the time – March, April, May, June - you don't have, you know and everything gets rolling, you know you don't really have a lot of time to catch up. It's almost like you need it instantly in order to keep that child staying on that path of their academics. (Participant 6)

Another parent explained that the frequency of the home instruction visits was inadequate. Both of these participants were satisfied with the quality of support that their child received from the home instruction, yet wished that they had received more. Although parents were pleased with the support that they received from the home instruction, one cancer survivor who participated in the study indicated that the teacher who came to his/her house was not supportive. When asked why the participant felt that way, he/she stated, "Well, he was kind of nit picky about things and wanted things done his way and only his way" (Participant 1a). In contrast to this, another cancer survivor who participated in the study shared that he/she was very happy with the teacher who did the home instruction and that he/she found it very helpful. Despite the case where home schooling was not seen as beneficial, it appeared as though families valued the support that was provided through home schooling and only wished that it could be put in place sooner and be more consistent than what they had experienced.

Re-entry programs

Having their child return to school following the treatment process and/or prolonged absence created anxiety for some parents and children. The experience of returning to school often involved a process of easing the child back into the school environment while also educating school staff and the child's peers of his/her situation. The majority of children represented in this study had a presentation done at their school upon their return. The presentation was done by a member of the parent support group and often involved both the child and sibling's classes. One parent summarized the presentation by saying,

She introduces herself, and she leaves a kit of some sort I know, with the school, like with the classroom so they can play with it and look at it. And I don't know how many of them actually pull it out of the suitcase, but it's there. She shows the video *Why Charlie Brown, Why?* She talks about her son and she shows a port and explains what it is. She introduces the child and if the parent is there, she introduces the parent and that sort of thing and she let's the kids ask all kinds of questions. She lets them know how sick the child is going to be, and losing their hair and basically all the symptoms that go with cancer and that sort of thing - missing school and being a special friend and that sort of thing. (Participant 6)

Two of the participants indicated that they did not have a re-entry presentation because they had not yet been connected with the support group at the time. One parent whose child was diagnosed and treated prior to entering school explained that he/she had meetings with school staff in lieu of a formal presentation. As one participant explained, "I don't know if that was ever done. I don't think it was, but even though it wasn't - somebody didn't go into the class and explain what was going on - there was always acceptance" (Participant 10). Based on the testimony of these participants, it appeared as though they did not feel that they were disadvantaged as a result of not having a presentation done. For both of these participants, school staff and peers were accepting and accommodated their needs despite not having a formal re-entry program. Although they were not at a loss, both participants indicated that they thought highly of the presentation that other children received and confirmed the benefits that these presentations provided.

For the participants who did have a formal re-entry presentation, the response to the presentations varied. Parents and children who did receive the presentations said that they were satisfied with the presentation itself. As one parent explained, "Because we had gone into the classroom and talked to the kids and shown the video, and with his hair loss and various things, they were just accepting" (Participant 2). This parent attributed the acceptance of his/her child's peers to the fact that they were educated about his/her condition. When asked if he/she was satisfied with the presentation and whether there was anything else that he/she wished was done to prepare peers, one parent responded by saying, "[Presenter]'s presentation was awesome. Like, no, I couldn't have asked for more than that" (Participant 6). Although all of these participants mentioned the benefits of the presentation, one family also noted that there was some resistance from peers when it came to the presentation. One participant shared his/her mixed feelings by stating, "It helped but I think they were still stuck up in their own ways and you know, didn't like me" (Participant 1a). This child's peers had made rude comments during the video that was shown as a part of the presentation.

The re-entry presentations that were done for participants included a number of features such as medical equipment, dolls, and a video. One participant said that he/she found that the video was the most effective feature of the presentation when it came to helping the peers understand the child's circumstances. Another parent mentioned the use of a different video and also described the medical equipment that was included in the presentation while sharing his/her views that these features added to the experience by making it more real for the peers. The participants who shared their experience of the re-entry presentation all indicated that both the child who had cancer and his/her parent(s)

were present during the presentation. The children were invited to speak about their experience with their peers if they chose to do so. One parent shared his/her surprise when his/her child took over the discussion during the class presentation and began to explain his/her circumstances to the group. The extent to which children participated in the presentations was left entirely up to them.

Some families had arranged for repeated presentations for various reasons. One child stated, “She did it every year just in case somebody else like new came to the school, so that people knew at the school that I had cancer” (Participant 6a). For this participant, presentations were done repeatedly as a way of ensuring that peers were aware of his/her illness. For another participant, the presentation was repeated as a result of recurring issues with peers. This participant stated,

I was having a lot of problems in grade five with people and so she did the presentation then. And I was starting to have a lot of problems again with people just like starting to make comments and such in grade seven, so she did another presentation in grade seven. (Participant 1a)

In this case, the presentation was done as a response to peer concerns. Since peer issues were believed to not only exist for children with cancer, but also their siblings, two participants spoke about having the presentation done for the siblings’ classes as well. One parent shared his/her belief that the presentations should include the entire school, rather than specific grades. With regard to presentations in siblings’ classes, one parent stated,

The sibling part of it is so important and they need that support...in some schools they do, you know, the whole school so that the whole school is a circle of friends

for the family and I think the more awareness is out there, the better support...the communities are amazing when the school knows about it. (Participant 2)

Participants in this study emphasized the value of having the peers and school communities educated about cancer and about each child's circumstances. Despite some resistance and challenging behaviour from peers, through the various tools and repeated opportunities for class presentations, participants in the study valued the presentations and felt as though they were an important part of their child's experience.

Educating the educators

The message that was communicated in the focus group and interviews was that knowledge and awareness often increased acceptance and support. One struggle that parents identified was the repeated need to remind the school that their child was still ill, or still needed special support, despite the fact that they were no longer in the hospital or receiving treatment. One parent shared these concerns by saying, "So I guess my main frustration was trying to get them to understand that you know, even though she was at school, she's still on treatment, she was still sick" (Participant 1). This parent was frustrated with the school for not informing him/her when children with contagious illnesses were at school or when they did not seem to understand that his/her child was often tired and needed breaks throughout the day. Another parent shared this frustration when working towards having certain academic accommodations and modifications put in place for his/her child.

Parents stressed the need to educate the educators. Four parents spoke of the need to provide educators with resources and education in order to increase their ability to adequately understand and accommodate for their child's needs. One parent said, "I don't

know if the teachers and principals and that know of all the resources that are out there and available” (Participant 13). Another parent suggested that teachers might have to do more research into childhood cancer in order to better understand children’s circumstances and make it easier for a child who has cancer. When asked what families felt could be done as a way to ensure that their child was supported at school, one parent stated, “You need the process of educating the educators, and I think the majority of them, if they’re given the education, they’ll help out” (Participant 5). Although participants acknowledged that making educators aware of a child’s circumstances is a key component in increasing support, they also recognized that there were other issues such as funding that also had to be taken into consideration.

Invisible disability

When speaking of the need to educate the educators, one of the main things that parents felt needed to be communicated was that their child did in fact have a serious illness that resulted in certain learning challenges. Three parents made reference to the term “invisible disability” when speaking of the challenge of having school staff acknowledge their child’s learning difficulties. When speaking of teachers and other school personnel not understanding his/her child’s needs, one parent explained, “Again I think just the whole scenario of the invisible disability that nobody sees that they can’t understand it unless they’ve kind of experienced it themselves” (Participant 1). Parents spoke about how many of the disabilities that their child had did not have physical signs. They also spoke of their frustration with the fact that teachers felt that their child should be treated as a normal student since they did not appear to have any disabilities. The

notion of their child having an “invisible disability” was regarded as a barrier to receiving support.

School climate

As a result of prolonged absences and potential academic challenges, parents spent a great deal of time interacting with school staff. When describing their own experiences, parents generally communicated that the atmosphere within their child’s school was positive. When describing a general sense of school climate, one participant shared,

It’s so school dependent, and there are some schools out there that are just so supportive...but then there’s also schools out there that are, you know, that you might as well pound your head against the wall because they don’t get it.

(Participant 3)

Many of the participants spoke of their child’s school in positive terms, using words such as supportive, accommodating and accepting. They explained that their child’s school was accommodating to their needs, especially when the child was still in treatment. When asked about the best part of the support that he/she received, one participant answered,

Oh, just the fact that I was accepted so much...I think I was one of the – the only child that had cancer in the entire school, so it was kind of maybe something new to them. But it was always - it was always accepted. (Participant 10)

Although this participant was the only child in his/her school who had cancer, three other participants indicated that their child’s school had experience with children who had cancer, which made the school better able to support their child. One parent said, “They’ve gone through four or five cancer patients in the last three years, so they’re

experts in this area” (Participant 17). The experience was believed to increase the understanding and support that the school was able to provide for these families.

Five parents and two cancer survivors spoke of establishing a relationship with the school. The nature of the relationships varied from feeling a sense of family closeness to maintaining regular contact while child was absent. One parent described his/her best example of school support by saying, “The best example is how the elementary school found a way where [child] went to – how they bought into the whole thing. It was almost an extended family” (Participant 5). When it came to easing parents’ concerns about their child being at school, one parent explained, “If things aren’t going well that day and he feels ill, they would call us right away. I think knowing that we had that great support there made a difference” (Participant 2). Knowing that the school would contact them provided parents with a sense of comfort.

Only one participant spoke of his/her child’s school climate in a negative way, describing the staff as intimidating. This parent illustrated his/her child’s experience by saying, “Once she finished treatment, then it became a different story to them because as far as they were concerned, the treatment was finished, everything was over with, get back to your normal life” (Participant 1). This parent believed that the support that his/her child received was adequate while his/her child was in treatment, yet sensed a change once the treatment had stopped. Participants who spoke of their school climate in favourable terms generally regarded their experiences as more positive than participants who felt that their school climate was less supportive and friendly.

Accommodations and modifications

Included in the many sources of support that participants were seeking for their child were accommodations and modifications. The accommodations and modifications that were made for the child varied according to individual abilities and needs. One accommodation frequently mentioned was the option for children to take extra time when writing a test or exam. There was also the possibility of changing the distribution of grades. One parent explained,

He would do really well on homework assignments, but then if he came to a test he never did as well just because he would get flustered and be overwhelmed. So, in that particular situation, the modification was that rather than having the test – say that the classroom work was worth - rather than being worth 10%, it might have been worth 30 or 40%. (Participant 2)

Three of the children represented in the study were removed from their classroom for remedial work. Of these three, two indicated that they did not like this and for one child, his/her parents arranged that he/she was no longer to be removed from the class. Two other children were granted access to the resource centre where they could choose to receive extra help with their work. Other accommodations for children included the use of a lap top, having a scribe for exams, help with editing and developing learning and organization strategies as well as the use of photocopies from peers or teachers. The photocopies were often provided for students who had trouble processing the information that they were required to copy down.

While children and families spoke of the benefits of these accommodations and modifications, four participants highlighted the fact that the children often did not want

the accommodations and special help if it made them stand out from their peers. Whether it was the use of assistive devices, having parents seen in school to meet with special education teachers, or being removed from class for remedial work, three parents and one cancer survivor spoke of the child's wishes to not have those accommodations. When describing his/her child's wishes to not be removed from class or use assistive devices, one parent shared, "She doesn't want to be different. She wants to be like everybody else" (Participant 6). Parents described their efforts to ensure that their children were being supported, while also recognizing their child's wishes to make the support as inconspicuous as possible. The availability of these accommodations and ensuring that they were exercised with care to remain inconspicuous enabled the children to succeed in their academics.

Principals

When discussing the support that participants received, the impact that various school staff had on the families' experiences was discussed. One theme that emerged was the notion that the experience of establishing and maintaining support for children who had cancer was very dependent on the principal of the school. Participants explained that the role of principals was separate from that of teachers. According to one participant, "The single most important person in the school, sadly, is the principal. Even though the student interacts with the teacher or teachers a lot more, you have to get the principal's buy in" (Participant 5). Being the head of the school, participants referred to the principal as the one to set the tone for the school. Participants believed that if they were able to obtain the principal's support, the teachers would have to follow suit. According to one parent, "The teachers dealt with everything daily and the principal was responsible for

getting the resources. So it's basically two separate roles right" (Participant 7). Five other participants also expressed their belief that it was the principal who was most important in allocating and securing resources for their child.

As a result of the reliance on principals in establishing and maintaining support for children, a change in principal often resulted in the participants' experiences also being changed. This change varied for participants with three participants stating that their experience improved as a result of having a new principal. One parent explained, "Well the principal changed this year and this year was smoother than the other two years" (Participant 12). However, three families described a decline in the availability of support for their child when the principal changed. Parents expressed their frustration with the degree of inconsistency as a result of principal turnover as this required them to spend extra time explaining their child's circumstances to the new staff in order to advocate for the necessary resources. One participant suggested that there be a resource at the school board level for schools to contact when one of their students is diagnosed with cancer. His/her reason for this would be to ensure consistency in the knowledge that school personnel have regarding cancer and the resources that children with cancer need as a result.

Parents agreed that supportive principals listened to students' needs and accommodated them. When describing his/her child's experience with supportive principals, this parent stated, "Having principals that wanted to listen and wanted to do the right thing and work with the parents, the teachers, to make sure that you know, the child academically succeeded" (Participant 3). Taking the time to learn about the child's needs, as well as working with the parents to negotiate the system and obtain resources

for the child, were examples that participants shared when describing supportive principals.

The discussion of principals also touched upon ways in which principals were not supportive of the children and their families. Some participants described their need to constantly advocate in order to have resources put in place. One parent described some principals as having a “wall up”. When recounting meetings with another parent to help speak to a principal, one parent shared, “I walked out of there and everything we had just talked about left, and it’s just – the wall was back up again” (Participant 3). Another participant mentioned feeling as though he/she received differential treatment that was based on income. According to this parent, “If you’re from the poor side of the street, you got nothing” (Participant 1). Although this parent was speaking of resources and support, he/she also shared an example of an incident where classmates were bullying his/her child and the principal was unwilling to intervene and help the child. Participants agreed that the role of the principal was crucial in determining the resources that their child was to receive and, as such, some principals made the process of advocating for these resources easier than others.

Teachers

Although the principals were defined as being the head of the school, participants agreed that the majority of their interactions were with their child’s teachers. According to participants of the study, a child’s, and subsequently their family’s, experience of being in school during or following treatment was dependent on their teachers. Parents described the shift in their child’s experience as their teachers changed over the years. For one parent, his/her child had a teacher who was very compassionate and understanding.

This parent explained, “You’re lucky if you have someone, one teacher like [child] had that was great for him, but one. What if I didn’t have that one teacher?” (Participant 12) At the time, the child enjoyed school as a result of the compassion that this teacher had for him/her. When the study was conducted, the child had a different teacher who the parent felt did not care about him/her, and as a result, the child no longer enjoyed school. Other parents described years where their child did not like school as a result of their teacher. The degree to which teachers showed concern and compassion for the child appeared to influence how the child felt about being in school.

In light of the impact that teachers had on a child’s experience of being in school, two parents described how their children’s teachers were preselected based on their expertise and ability to meet each child’s needs. One parent made the request on his/her own while another parent explained that it was the special education teacher who preselected his/her child’s teachers. Three families mentioned having the assistance of special education teachers and guidance counsellors. Two of these parents spoke very highly of the support that they had received from these teachers. When speaking of the importance of teachers, one parent mentioned the work that the special education teacher had done for children who had cancer. This parent stated, “He’s been such an advocate for our kids and what have you, it’s phenomenal” (Participant 3). With that being said, another participant shared his/her frustration regarding his/her interactions with a different special education teacher by saying, “She’s got a wall and she’s very overbearing and overpowering and she seems to make you feel belittled I guess and somehow get lost when you’re talking to her” (Participant 1). In this situation, the parent

felt that the special education teacher was not acting as a facilitator of support for his/her child.

Non-supportive teachers.

While some teachers were described as helpful, there were a number of instances where teachers were perceived as not supportive. One of the most frequently mentioned indicators of a lack of support was a teacher not understanding the needs of the child. Four participants made reference to teachers not understanding their child and spoke of how it influenced the child's experience. One parent stated, "Grade one was a horrible year, but again it was the teacher and the teacher not understanding" (Participant 3). When asked about his/her worst experience at school, one cancer survivor answered, "That nobody really like understood my needs, even the teachers" (Participant 1a). This participant had the expectation that teachers would be understanding of his/her needs, however he/she felt that this was not happening. Similar to not understanding, participants also cited teachers not listening to parents' and children's concerns and not seeming to care as examples of ways in which teachers were not supportive.

Similar to not understanding and not listening to children and parents, it was evident that some teachers did not comply with or read the child's IEP. Three participants mentioned that they felt the need to speak with each of their child's teachers in order to ensure that they were made aware of the child's circumstances. One parent shared his/her experience by saying, "I try and meet with the teachers like when they have their mid-term thing or whatever, but sometimes I have tried to meet them before that period...because I realize that they don't always read the IEP" (Participant 1). Despite parents' efforts to inform teachers of the IEP, four participants indicated that there were

times when teachers did not comply with the stipulations that were on the IEP. One parent mentioned the teacher's refusal to make any of the modifications that were specified in his/her child's IEP. The degree of non-compliance with the IEP varied from teachers not being willing to provide extra help, to the extreme of forcing a child to participate in physical education class despite doctors' recommendations. This participant explained,

Well my grade eight teacher wasn't very accommodating if I didn't feel well. He made me participate in phys ed and stuff and body contact sports when we even got a letter from my neurosurgeon saying no body contact sports. (Participant 1a)

Three parents shared their belief that the teachers who did not comply with the IEP and who were seen as unsupportive did so because they were "set in their ways".

Regular classroom teachers were not the only ones said to influence children's experience of being in school. Three parents shared stories about their child being upset by supply teachers who did not appear to understand their circumstances. For one child with a hearing impairment, the supply teacher refused to wear the microphone for the FM system, which was a requirement stated on the child's IEP. One other parent shared a different experience where the supply teacher was almost too accommodating. This parent explained,

Her teacher that we had went on sick leave for six weeks and we had a supply teacher come in and she went into school so excited because she got to go back and he says, "Oh you don't need to do this dear, just sit there." She said, "I'm not going anymore. I'm not here to just sit in a chair." She was angry because the teacher didn't do what she expected. (Participant 13)

These parents felt that the supply teachers, especially when working in the classroom for an extended period of time, needed to be more aware of the child's background and needs in order for them to provide adequate support for the child. The perceived lack of support and understanding from some teachers created added stress for participants and appeared to have a negative impact on their experience.

Supportive teachers.

Although there were instances of non-supportive teachers, ten participants shared their experiences with teachers who they felt were very supportive. Parents and cancer survivors felt that they received support from teachers who maintained contact with the family and developed relationships with parents and children. One parent said, "My son's has been very positive, again, the teacher has been fantastic both years that my son has been at school...they really kept him involved in the classroom" (Participant 4). Participants mentioned visits home, phone calls and daily communication books as ways in which they felt supported by teachers.

Sensitivity and showing concern for the child were also ways in which teachers appeared to be supportive of children and their parents. When asked about what one child liked about his/her teacher, he/she responded, "Because she always helped me out with my work and always helped me if I was upset or something" (Participant 6a). Listening to the child and the parents was described as a way that teachers demonstrated their support. One parent stated, "That made her feel really good because here's a teacher at school actually listening when she's saying, 'I'm tired, I can't do it'" (Participant 1). Parents appreciated when their child's teachers were understanding of their circumstances and did not push them if they were not well.

From an academic standpoint, parents made reference to their appreciation of teachers who provided their child with extra help. One parent shared, “He had teachers staying after school, and this is elementary school and high school. After school through elementary school, or before school if necessary. In terms of being with him and giving him additional counselling or additional help” (Participant 5). Five participants expressed their satisfaction with certain teachers who provided extra help in order to help the child succeed. As teachers changed over the years, so too did participants’ experiences and perceptions of whether or not teachers were supportive. There were no participants who spoke of having only unsupportive teachers throughout their experience and only one participant who referred to all of his/her child’s teachers as supportive.

Educational Assistants

In addition to the children’s daily interaction with teachers who were a source of support, Educational Assistants (EAs) were also mentioned as a source of support for some children. EAs were put in place for three of the children represented in this study. Two of these children received shared support, meaning that their EA was responsible for them and other students as well, or students had a change in EAs throughout the day. One family felt that this was adequate, however another parent shared, “Now she has three separate EAs, it’s not, she’s not getting the same attention that she used to” (Participant 17). This parent was concerned that there would be times during the day that his/her child was not doing anything because there was no EA available to help. EAs were said to have provided students with academic support as well as physical support when necessary. Interestingly, it appeared as though not all children were cognizant of the reasons as to why they had the assistance of an EA. One child shared his/her perception

of how his/her EA helped by saying, “She had to push me in a wheelchair. She had to follow me everywhere every recess to make sure I didn’t get lost or I died from the cancer taking over my body or something” (Participant 6a). According to this child’s parent, the EA was put in place as a safety measure as a result of physical limitations resulting from the treatment. This child, along with another cancer survivor, also indicated that the EA provided academic assistance. Parents agreed that having an EA in place was an effective form of support.

Additional sources of support

The objective of this study was to learn about how children and their families experienced being in school following their diagnosis and/or treatment. Although the questions that were asked focused on school support, participants also mentioned a number of support systems that contributed to their experiences, which were not related to school. These varied from medically related supports and cancer organizations to family and church groups. Three families mentioned the help that was received from an Interlink Nurse who was provided through their treatment facility. One parent described the services provided by the Interlink Nurse by saying, “She’s the one that linked me up with all the agencies. She’s the one that helped me with getting like, respite, which is something a lot of families don’t know” (Participant 6). This parent felt fortunate to have the support of the Interlink Nurse, however this position was only recently created, therefore this resource was not received by all who participated in the study. Other medically related supports that were mentioned by participants included Physiotherapy and Occupational Therapy. Occupational Therapists were said to have provided some children with adaptive devices to help them in school.

Other significant sources of support for families who participated in the study included organizations developed specifically by or for those who are affected by cancer. One participant stated that his/her best experience in terms of receiving support was from the Cancer Society who provided the family with rides to and from the hospital for treatment. The Pediatric Oncology Group of Ontario (POGO) was also listed as a source of support. Along with this, one parent mentioned connecting with other cancer support groups. As discussed in the section that focuses on siblings, camps for children affected by cancer were also mentioned as a source of support for families. For one child who received his/her treatment as a baby, his/her parent explained, "There's been a lot of vicarious learning through the camps and things like that for her" (Participant 3). This child had learned more about cancer through interacting with other children at camp. Finally, the support group from which participants were recruited was described as a source of support for children and siblings as well as parents. Participants mentioned the teen group and expressive art therapy program that were facilitated by this support group. When speaking of the art therapy program, one parent explained, "That seemed to help [child] in a sense to get her confidence back in herself" (Participant 1). Both siblings and children who had cancer were invited to participate in these programs.

Members of participants' churches were described as providing support for children and their families. Two of the cancer survivors who participated in the study revealed that the church offered some support. Two other parents who participated in the study also shared the importance of family members or friends supporting their families. When speaking of the support that his/her family received from other family members, one participant explained,

It helped out- I know you're going to do your focus on the school there, but it would help out indirectly with school. It could be something as simple as looking after siblings, you know, to take them to their soccer lessons or soccer games or hockey games or something like that, to making a meal. (Participant 5)

This parent shared the fact that families are exhausted from the cancer experience and that the help and support that friends and family were able to provide was one of the most important sources of support during his/her child's treatment. Participants appeared to appreciate and value receiving support from a variety of sources that were separate from the school itself.

Support recommendations for other families

Those who participated in the interview phase of the study were asked what advice they would give to other children or families who were about to begin their own cancer journey. Asking for help was one recommendation made by three parents and two cancer survivors. When asked what he/she would say to another child, one cancer survivor said,

I would say don't be worried about any needles or any surgery you get because everything is going to be fine...you may miss a lot of school but I'm sure you'll get through it and I'm sure people will help you with it. (Participant 6a)

Interestingly, one parent spoke of his/her experience of being offered help, while not knowing exactly what help to ask for at the time. Looking back, he/she suggested that families ask for simple things such as a meal or for someone to sit with their child so that the parent can have a moment to relax and take things in. As a message to other families, one parent said,

There are a lot of parents out there who want to help. We've walked those shoes.

We've had them on. We don't want to wear them again, but we will if we have to.

Let's go arm in arm to take care of this. If we have to we will. We don't want to,

but we will...there's a lot of people out there who want to help, who've been

there and want to help. (Participant 3)

Participants were very clear in their suggestions that families need and should have help throughout the experience whether it is from friends, family or other families who share similar experiences.

When discussing ways in which support services and access to those services could be improved in the future, three parents shared their opinion that families need to have improved access to information relating to support services right at the beginning of their experience. As one parent described,

It takes a year to – everything just to sink in and fall into a routine with the hospitals and everything. Then you start looking around at all the different resources because by then you've spent all your resources right, you've used up everything. Something at the beginning needs to be done. Somebody needs to help you establish everything right off the hop. (Participant 7)

Two participants suggested that a source for providing school personnel with information and resources relating to childhood cancer also be established. Support groups for teachers as well as a position at the school board level were suggested as ways to ensure that schools were aware of the circumstances and able to support the children. One participant also stressed the importance of having a paid advocate position in place in order to help families navigate through the school system and advocate for support and

resources. The message conveyed was that support for children who have cancer and their families should be standardized. It was also recommended that families ask for help from others and be made aware of, and take advantage of, the support offered to them by other families who share their experience.

Siblings

Although the experience of a cancer diagnosis and treatment has many implications for the patients themselves, there are a number of ways in which the siblings of children who have cancer are impacted by the experience as well. While much attention is focused on the child who has cancer and his/her parents, siblings of children who have cancer are often forgotten. One parent of a cancer survivor indicated this by stating, “If we’re the invisible patients, then siblings are the forgotten patients” (Participant 3). Although seemingly forgotten, siblings of cancer patients and survivors often experience an interruption in their regular routines and life events and may have a number of misconceptions regarding their siblings’ own routines and changed lifestyle. When discussing the impact that the cancer experience had on siblings, issues such as a change in routine, emotional reactions and changes in family dynamics and relationships were examined. Also included in the discussion was the nature of siblings’ peer relationships as well as support services that families accessed for their healthy child/children.

Forced change in routine.

Although the majority of attention throughout the cancer experience is placed on the child who has cancer, siblings of these children were often impacted by the

experience as well. One way in which siblings were affected was through interruptions in their own routines. With regard to siblings' events being interrupted, one participant recalled, "Her birthday parties, her special – I was supposed to go and help in her class one time and then her brother got sick and I couldn't go" (Participant 2). This, along with parents being unable to attend sporting events or dance classes, is an example of siblings experiencing interruptions in their routines. One parent described a conversation with his/her healthy child years after the cancer experience in which the healthy sibling shared a memory of a time in which he/she was very jealous that the family had to make a stop on a way to his/her special sporting event in order to accommodate one of the medical needs of the child who had cancer. According to this parent, the healthy sibling shared his/her feeling of jealousy that his/her event was delayed as a result of the child who had cancer. These interruptions did not go unnoticed by the parents, and a number of participants described their efforts to keep their healthy children's routines as normal as possible. One parent described his/her efforts by saying,

So if the kids had gymnastics or dance... we were calling in favours all over the place just to make sure that our kids got to their dance...and just trying to do everything, you know, as I guess we all do just to make sure that they stayed the same, or trying to. (Participant 11)

Parents described having friends and family members help to keep the siblings' routines as normal as possible throughout the cancer experience. Although families aimed to maintain consistent routines within the family, the health of the child who had cancer was their primary concern and as a result, routines were often interrupted. Parents described a

number of emotions that siblings expressed as a result of these interruptions as well as other aspects of their experience.

Emotional reactions.

While parents described their efforts to minimize the implications that the cancer experience had on their healthy children, many parents in the study acknowledged a number of emotional reactions that their children had as a result of the negative implications mentioned above. Emotional reactions varied in nature ranging from jealousy and anger to empathy and concern.

In many families who participated in the study, parents indicated that their healthy children expressed a fair amount of jealousy and anger. In many of these cases, these emotions were a result of the amount attention that was given to the child who had cancer rather than the healthy siblings. As one parent noted in an interview,

I think in some ways it was still a jealousy, the fact that the one that was sick, because he had all those needs, was getting more attention...we tried to keep things as normal as possible, but no matter what, you're giving more attention to the one that's ill, and they feel it, and it's hard. (Participant 2)

Anger and jealousy were frequently noted as a combined emotional reaction by parents. One parent shared the example of his/her child reacting to questions about his/her sibling who had cancer by saying, "There was a lot of anger and jealousy there...she wanted some of the focus to be on her and not her sister anymore" (Participant 13). While families provided examples of their child's anger and jealousy, one parent also expressed that he/she was unaware of the extent of his/her healthy child's jealousy until years later.

Two families in the study indicated that they believed the anger and jealousy that resulted from the cancer experience contributed to aggravating or increasing existing emotional and behavioural problems in their healthy children. While one parent attributed the increase to the shift in parental attention, another explained his/her inability to determine whether it was as a result of his/her child's illness or just coincidental that his/her healthy child's issues were worse. This parent explained,

Well his problem got a lot worse, but whether or not it wouldn't be any worse if she hadn't been sick, I can't say because he does have his own problems that are probably always going to be his own problems. So, I just think her being sick made his much more harder to deal with. (Participant 1)

Other parents whose healthy children had existing issues all acknowledged that the issues were not a direct result of the cancer experience, although they may have been compounded by it. One parent stated that the cancer experience had no influence on his/her healthy child's diagnosis of Attention Deficit Disorder (ADD) despite suggestions from friends and family. This participant said,

She was getting, she got diagnosed that year because everybody kept telling me, "Oh it's because her sister's sick, her sister's sick," and I'm like, "Nope, something's wrong with her. She can't focus." Grade two I had her diagnosed. By grade three, end of grade two I had her diagnosed, by grade three she was put on medication. (Participant 6)

One family shared their belief that educational and emotional concerns exhibited by their healthy child were a result of him/her internalizing the events that were taking place. This child's parent explained,

He internalized so many things himself and the more paying attention and had to do with [names child who had cancer], the more he internalized things to the extent that we ended up having to change schools because we thought in fact that he had a learning disability ...ironically, he turned out to be the brightest kid academically out of all three kids. (Participant 5)

In this instance, attending the same school and being in the same environment as his/her sibling who had cancer had a negative impact on this child that temporarily caused the parents to believe that there was an issue. Once this child found his/her way into a separate environment, he/she appeared to excel and the problems that had appeared soon diminished.

Anger, jealousy and the intensification of existing problems were common sibling reactions discussed by the families who participated in the study. Although these reactions can be viewed as somewhat negative, a number of families shared that their healthy children exhibited a high degree of concern about their siblings who had cancer. One family indicated that they did not know of this concern until they spoke to the parents of their child's friend. In another instance, the concern for a child's sibling who had cancer was exhibited through a change of behaviour and expressed concern. This parent explained,

I mean she'd always start sleeping with us again, and we had just broke her out of the habit. She started sleeping with us again and having wicked nightmares and what not and reading cancer books and just saying, "I don't want [sibling who had cancer] to die, I don't want [sibling who had cancer] to die," or, "Is that what's going to happen to [sibling who had cancer]". (Participant 17)

Another parent noted that his/her children would discuss the possibility of death with each other.

In contrast to anger and jealousy, and perhaps as a result of worry and concern, parents also noted an increase in empathy among their healthy children as a result of the cancer experience. One parent emphasized the increase in sympathy that his/her child exhibited towards his/her sibling who had cancer. Another parent mentioned a camp that is geared towards children who have cancer and their siblings and how the nature and design of the camp activities affected their family and taught his/her children about empathy. Speaking about the camp, this parent said,

It's very empathetic. There's a lot of very positive energy. A lot of positive things that the children are surrounded with, right, and me, I don't know if this never happened to us, if the kids would have gotten that same sort of experience – like that positive, sensitive experience right, to teach them empathy and how to respect somebody else when they're not doing well. (Participant 7)

It appeared that the emotional reactions that siblings of children who have cancer vary greatly. Whether these emotions are directly a result of the cancer experience or coincidental is something that parents say they cannot determine conclusively. Regardless of this, the emotions experienced and expressed by the siblings do contribute to the overall way that children and their families experience cancer.

Role in the family.

Siblings of children who have cancer may also be affected by a shift in the role that they play within their family. When examining the impact on family dynamics, it was interesting to note a change in roles that was experienced in three of the families who

participated in the study. Role changing included one instance where a younger sibling took on the role of the older sibling. During the focus group, one parent stated, “They have changed roles too. [Sibling of child with cancer]’s taken the role of the older sister, helping [child with cancer] and doing stuff for her” (Participant 16). Along with siblings helping each other, one of the children who had cancer who participated in the study acknowledged that his/her healthy sibling had helped him/her and explained, “Yeah, she was helpful, like if somebody bullied me I would go right to her and she would deal with it” (Participant 6a).

In addition to helping their sibling who had cancer, three healthy siblings were also said to have taken on a mothering role within the family, helping out in other ways. One family witnessed this through their healthy child cleaning and disinfecting the house and decorating for a holiday while the mother was at the hospital with his/her younger sibling. Another family noted that their child took on a mother figure when dealing with his/her younger siblings, including one who had cancer, but also said that,

She tried to be too much of an adult as a child...so she put on you know, the brave face type of thing. You know, didn’t want to bother mom and dad, “Even though I’m really bothered by this, I understand mom and dad are going through all this.” (Participant 5)

In all three of these cases, the siblings who took on either a mothering or caregiver role were female. No mention of these role shifts were made for male siblings, although there were only two male siblings represented in the interview portion of the study where majority of the discussion on siblings took place.

Relationship between siblings.

Just as the cancer experience can result in a range of emotions, accompanied by a change in family dynamics, there is also the possibility that the relationship between siblings can also be affected. When speaking to participants about the impact that the cancer experience had on the relationship between their children, findings appear to be divided. Seven participants, representing five families, spoke about the quality of the relationship between their children. Three families indicated that their children became closer as a result of the cancer experience. One parent explained, “But they are really close, I think because of the whole situation. So if you’re looking for a positive out of it, they became best friends” (Participant 7). All three of these families expressed that this closeness was a positive outcome of the cancer experience.

In contrast to this, two participants spoke about their children not being as close to each other after the cancer diagnosis. One parent described how, “There’s a real rift between my girls” (Participant 13). Both of these parents acknowledged that the relationship between their children was improving, however their relationships were not where they had been prior to the cancer experience. Although the ways in which the sibling relationships were affected differed, it is evident that the cancer experience does play a role in re-shaping the relationships that siblings have with each other.

Peers of siblings.

The changing nature of the relationship between siblings points to the possibility of the nature of siblings’ relationships with their peers changing as well. When discussing the relationships that healthy siblings had with their peers, five participants, representing three families, shared an overall impression that they felt that their healthy children had relatively supportive peers. Acknowledging the everyday challenges of friendships, one

parent explained that, “Girls at a certain age have struggles with peers and stuff, but I think overall that she had good support from key friends” (Participant 2). Another parent indicated the longevity of his/her healthy child’s friendship by stating, “That friendship has never strayed and it’s always still there” (Participant 7). These parents described their children as having a supportive group of friends, with particularly close friendships with individuals within these groups.

Along with being supportive of the healthy siblings, two families described the support of the siblings’ peers extending to their child who was ill as well. In some instances, it appeared that the siblings were sharing friends. In one family, it was the friends of the ill sibling who were supporting the healthy child. According to one parent,

All of [child who has cancer]’s friends took her in as a little sister and watched her day in and day out at school and were walking her home from school and staying after school and playing with her and doing everything like a big sister would. (Participant 17)

In another family, it was the friends of the healthy older sibling who extended their support to the child with cancer by inviting him/her to parties and putting up with him/her more than they normally would.

While most siblings appeared to have positive support from their peers, one family did indicate that one of their healthy children’s relationships was not as supportive as the relationships that their other children had. This parent indicated the difference in the quality of the peer relationships by saying,

Other people have come and gone in his life and he just doesn’t seem to have the same support system as the other two...not that he doesn’t have friends, he has

lots of different friends, but I just don't get the sense of the same type of support system that the older two had. (Participant 2)

This family indicated that as a result of this child attending a different school than his/her sibling who had cancer, the parents were unsure of whether his/her peers were even aware that his/her sibling was ill. In this case, the lack of support was related to the child's personality as his/her parent stated, "I don't see the same kind of support because he was more quiet and introvert[ed]" (Participant 2). Interestingly, the siblings who appeared to have more positive peer relationships were females, while the relationships lacking in support were male. One might wonder whether the differences in support relate to overall gender differences in peer interaction and relationships.

Support for siblings.

Returning to the notion of siblings as the forgotten patient, it is important to understand the support systems that are available to siblings as they live through the cancer experience. While peer support is mentioned above, families shared information about their perception of support in the schools, in community groups and camps as well as their expressed need for additional sources of support for healthy siblings.

Two parents who represented the same family expressed the need for sibling support within the school system. The link between school support and peer support was made clear when this parent stated, "Again the big push on this is the more you educate the school, the more you educate the kids in the school and also the kids of the siblings – because the siblings are very much affected by it" (Participant 5). Sibling support within the school setting was discussed primarily in conjunction with the need to educate the school about the needs of both the child who has cancer as well as the sibling. One parent

stated, “I think that teachers need to know that the siblings have different problems as well” (Participant 2). It was made clear that these parents viewed schools and teachers as a source of support for healthy siblings.

In addition to peers and the school itself, five parents described their use of additional sources of support for their healthy children that were available through the cancer community. The support group from which participants were recruited had organized an art therapy program that was accessed by a number of the healthy children of the participants in this study. Two families mentioned the teen group that was also run through the support group to which siblings and children with cancer were invited. Outside of the support group, two families mentioned the value that special camps geared toward families experiencing childhood cancer had for their healthy children. One parent described the benefit of this camp by saying, “I think being at camp helped him just have something for himself but also be with people that understood” (Participant 2). Similar to camp providing a separate environment for siblings, one family described their use of a program geared solely towards siblings of children who have cancer that is based in the United States. This program recognized the impact that the cancer experience has on siblings and rewarded them through special mail, bravery programs and a certificate at the end of the cancer treatment. When asked if the parents found that this program was helpful for their healthy child one parent replied, “Oh did it ever! Oh my, yeah!” (Participant 6) It was explained that this program did not involve the child who had cancer and was therefore something special for the sibling to have that was his/her own.

Families who utilized these support resources were appreciative of them, however it was noted by three families that there is an existing need for additional support services

for siblings of children who have cancer. One parent who had found the support services for his/her healthy child to be insufficient explained,

There are very few places where children can go today to I guess air their concerns about their siblings with – living with a sibling who has cancer or who has had cancer. There's nothing out there in our local area anyway. (Participant 1)

These parents expressed their desire for the variety and availability of support services for siblings to be increased.

Advocacy

Those who participated in the study frequently mentioned having to advocate for their child as well as teach their child to advocate for him/herself as a way to ensure that they received the necessary resources. One parent emphasized the importance of advocating by saying, “Yeah you have to, you really have to advocate for your kid. You have to! There is no, *you maybe should*. You can't – you have to. That's their only voice” (Participant 6). In describing their efforts to advocate for their child, parents indicated that they often had to remind school staff of the child's needs and needed to be proactive in order to ensure that their child was receiving the support that he/she required. Three parents felt as though they had to convince school administration that their child did in fact require support. One parent shared, “It's really sad and frustrating and like – to convince them to get, you know, for [child] to have a tutor” (Participant 12). This parent and five others explained how they had to consistently return to the school in order to advocate for their child. Parents indicated that they advocated in order to have school staff understand their child's needs and provide modifications, accommodations, and resources to meet these needs. One parent shared,

What I discovered in the school system is like as a parent you have to continually advocate for an understanding of what might be needed. So it was up to us to verbalize, and I felt that we had to do it on behalf of [child] because he just didn't want to have to be discussing the fact that he had some weaknesses or challenges, which is very normal for kids at that age because they don't want to be singled out. (Participant 2)

Although parents were advocating for their child, four parents spoke of their efforts to encourage their child to advocate for him/herself. These parents urged their child to communicate their needs with their teachers and to speak up in the event that prearranged resources or accommodations were not being provided. One parent explained that his/her child's school was also suggesting that the child advocate for him/herself, rather than having the parent intervene, however this parent felt that although the school was asking for the child to advocate, they were not listening to what the child had to say.

For these families, advocating for their child was a continual process. Participants explained that they had to advocate a lot in order to ensure that their child received support. Four parents shared that they had help from either a member of the support group and/or members of their child's medical team by attending meetings at the school to attest to their child's needs. Parents described the struggle to find the time to advocate for their child since it was such a demanding and constant process. When discussing his/her success in establishing resources for his/her child, one parent stated,

Again, this is after a ton of fighting and advocacy. You know, again, most parents don't have the time for that and as a result they give up and the child doesn't have

the proper resources to be able to adapt or to be able to achieve a certain educational level. (Participant 5)

Parents described the strain that advocating created for them since they were generally very overwhelmed with the demands that the treatment and medical aspects of their child's condition placed on them. One parent stated, "As a parent, you're so involved in the treatment, you're exhausted, you don't have time to be talking to the schools" (Participant 2). In a number of families, the parents divided the responsibility of working with the school on a regular basis in order to ensure that the child's needs were met. However, while parents worked together, there was generally one parent who was more involved with the school than the other. Advocating appeared to be a demanding, yet compulsory task that families had to take on in order to ensure that their child's needs were being met.

Fighting

Throughout the discussion of advocating for their child, parents referred to the advocacy and their interactions with the school as a "fight". When referring to the fact that they had to consistently advocate for their child, two participants referred to advocating as an "ongoing battle". One parent went on to say, "But by that time, of course again, I'd gotten used to fighting with everybody for everything so for me it was like, 'Here we go again'" (Participant 1). This battle was said to take place over a course of years due to changes in principals and teachers, and for those whose child was in high school, it was each semester with a number of different teachers.

When it came to fighting with teachers, parents were often fighting to ensure that certain accommodations and modifications were in place. One parent described his/her

experience with a teacher by saying, “I think my husband thought he was going to have to hold me down because this teacher just didn’t get it” (Participant 2). Despite having meetings with teachers, principals and special education staff, parents often encountered teachers who were not understanding and accommodating of their child’s needs. Despite this, one parent indicated, “You were generally fighting the system more than the teachers” (Participant 5). Along with fighting the system for support and resources, participants also referred to themselves as having to fight their way through the system in terms of learning how to approach certain issues and learn about what their needs were and what resources were available. During this conversation in the focus group, one parent explained, “We’re fighting at a time that we shouldn’t have to be” (Participant 11). Participants agreed that with the strains placed on them and the medical demands that they were faced with, they should not have to be fighting with the school in order for their child to receive necessary resources and support. The frequent references to advocating as a “fight” indicates the degree of emotion and perhaps frustration that families experienced throughout this process.

Being Normal

In addition to references to not wanting to be different, throughout both the interviews and the focus group, participants repeatedly made comments emphasizing their wish to be “normal”. References to normal seemed to reveal participants’ perceptions that cancer was abnormal and this was supported by how participants described their families as striving to have their lives return to normal. Participants spoke of maintaining or returning to a normal routine or having a normal life, or being a normal kid. Both parents and children wanted the children to be normal kids and fit in with their

peers. One parent described his/her child's efforts to be normal when explaining that despite the availability of assistive devices, his/her child refused to use them. As this parent explained, "She wanted to be normal like everybody else, so she's opted out of using them" (Participant 6). Other children who were represented in this study also disliked having visible support since it made them seem different from their peers, which was considered abnormal.

Although children strived to appear normal and similar to their peers, two parents shared their belief that teachers and principals were reluctant to provide support and accommodations because their child appeared normal and did not have any visible signs of their condition once they had finished treatment. One parent shared, "So they said, 'Oh, he looks normal, we're treating him as normal and we're not doing anything different for him.' And so, you know, so it, you know, that was a frustration" (Participant 5). These participants indicated that their child's normal appearance acted as a barrier to receiving necessary support.

Throughout the study, cancer was referred to as being abnormal and families were constantly striving to achieve a state of normalcy. Being well enough to attend school was an indicator of being normal for participants. One parent described his/her dilemma in deciding whether or not to send his/her child to school due to the uncertainty of the child's condition, but stated,

The most important thing was to let that child live in the present, live in the moment and do normal things. And the more they went to school, and the more they maybe didn't think about the cancer, and it was always, what I feel, is the important – like the nice environment where they can just be a kid. And it's not a

hospital, they're not getting needles, they're not getting medication and it's the one kind of protective environment for them where they can just be themselves.

(Participant 2)

School was said to be a normal part of childhood and was a normal environment for both children who had cancer as well as their siblings.

Parents described their attempts to balance their child's health and medical needs with being in school. One parent experienced anxiety when his/her child returned to school, but stated, "It was nothing to do with school environment. It's just having to find the balance with the medical needs and the health with the normalization of school"

(Participant 2). Three parents mentioned that they were worried about their child catching illnesses from other students. One parent explained,

So it was great that she was going to school, but then I was also scared of the outside ailments, which were like the chicken pox, you know, like any type of illness that was going to get her sick. Infection was my biggest thing because that would just put us back in the hospital. (Participant 6)

Parents explained that they had arranged for schools to call them if their child was not feeling well or if the school had been made aware of any other peers who had contagious illnesses. Although parents were worried about their child becoming ill, as one parent said, "I just wanted to get her back to normal as fast as possible. Just throw her in there and hope for the best" (Participant 7), they wanted their child's routine to return to normal. Since school was seen as normal, parents chose to put aside their fears of illness and have their child return to school. It appeared that although cancer had become a major part of these families' lives, it was still viewed as abnormal and efforts were

consistently being made to restore a sense of normalcy in the lives of the family members.

Differences in Experiences Between Families

The participants in this study were recruited through a regional parent support group that met regularly to share their experiences. In speaking with participants, many often described their own experience and then compared that experience to the experiences of other families who were a part of their group. In all cases where this happened, participants spoke of themselves as being more fortunate than others. When speaking of principal and teacher support, three families had indicated that their experiences were positive in relation to others. One parent stated, “We were fortunate that we had what we did. Not everybody gets that. I mean, it’s harder for other families” (Participant 6). Parents who received support, or felt as though the school staff understood their needs, all acknowledged that they were fortunate and recognized that some other families did not receive the same quality of support.

Experiences also differed when it came to social aspects of the cancer experience. When discussing behavioural changes in children throughout the cancer experience, one parent believed that his/her child had become more outgoing and social as a result of having to interact with a variety of people in the hospital setting. When comparing this result to other families, this parent explained, “It’s kind of interesting because we know another family that it’s probably the opposite. Sometimes they become shelled. They just keep to themselves because you know, they’re loosing their hair, or they’re not quick developmentally or grasping stuff” (Participant 5). When discussing peer relationships, comparisons were made between children who did not exhibit any concerns and those

who often did have issues with peers. Overall, although participants indicated that they had to fight in order to receive resources and support for their child, it appeared as though they believed that they were more fortunate than other families that they know.

Discussion

The return to school marks an important time in a child's illness experience, as it is a major component for a child returning to the normal routines of everyday life (McCarthy et al., 1998; Sullivan et al., 2001). As Sullivan and colleagues (2001) assert the importance of school re-entry on a child's social survival, it is imperative that the ways in which childhood cancer survivors and their families experience being in school be understood. As such, this study aimed to explore the lived experience of being in school following a cancer diagnosis and/or treatment from the perspectives of the children who have cancer as well as their family members. The exploration focused on challenges resulting from the illness and/or treatment such as cognitive, physical and behavioural changes as well as social issues and families' perceptions of the support being received. The impact that the cancer experience has on healthy siblings was also examined. In addition to these themes, a number of themes emerged from the data, including issues related to advocacy, what it means to "be normal" and differences in the lived experience among families.

Challenges Associated with Cancer

The various changes that children experienced as a result of their illness and/or treatment were discussed and reviewed. Included in this discussion were descriptions of the physical changes and side-effects that the children underwent and how these

influenced the child's experience. In addition to the physical changes, side-effects of their treatment often resulted in children experiencing cognitive impairments and academic challenges as well. Changes in behaviour, although not noted by all parents, were also discussed.

When discussing the cognitive, physical and behavioural changes and challenges that children experienced, it was clear that they did not want visible support or assistance if it resulted in their appearing to be different from their peers. This was evident from explanations of children refusing the use of assistive devices and expressing their unhappiness with being taken out of their regular classes in order to receive individual academic support.

For some participants the locus of difference was in the physical changes that were the result of their disease and treatment. Some described a number of physical changes that resulted in their appearing different from their peers. These physical changes were said to be a result of the side effects from their cancer treatment. These physical changes included changes in appearance and physical abilities, weight loss and/or gain as well as lower energy levels and increased hunger. The discussion of physical side effects was similar to Keene's (2003) description of short-term side effects including baldness and weight-loss or gain. Participants described the impact that these physical changes had on their peer relationships, indicating that peers had a hard time relating to them as a result of their changed appearance, thus putting a strain on their relationships with peers. This relates to Fraser's (2003) discussion that suggested that classmates may react negatively to a child who has cancer as a result of their focusing on the ways in which the child had changed physically, and not knowing that the child is the same person with

whom the classmates were once friends. When discussing parents' concerns during their child's re-entry, Eiser (2004) and McCarthy and colleagues (1998) both indicated that parents seemed more concerned with the physical and social aspects of their child's re-entry than with academic aspects. This is similar to findings in the current study where parents described their concern about their child's acceptance of their lack of ability and physical changes and ways in which peers would respond to these changes.

Participants of the current study described the cognitive impairments and academic challenges that their child experienced as a result of the illness and/or treatment. Research from Mulhern and Palmer (2003) indicated that many of the academic changes that cancer survivors experience do not begin to develop until two to four years following treatment. This corresponds to the current findings where participants described the timing within which they began to notice the changes in their child. Cognitive impairments that were manifested in the school setting for participants of the current study included memory problems, delays in thought processing and difficulties with organizing and multi-tasking. Armstrong and Mulhern (1999) also mentioned trouble with memory and mental processing speed, but included problems with attention and intellectual deterioration as well. Participants in the current study did not note these. The cognitive impairments experienced by participants of the current study appeared to manifest most commonly in language and math, with most participants describing these subjects as being the most challenging for children.

When discussing the physical and cognitive implications of the children's treatment, some parents spoke about changes in their child's behaviour as well, however, there was no consistent finding that indicated behavioural changes within this group of

participants. Although some participants noticed changes in their children, other parents stated that they were not aware of any changes in their child's behaviour.

Overall, participants indicated that the most significant changes that the children had experienced were cognitive, which created academic challenges for the children. Following the cognitive changes, physical changes were also noted by a number of participants, and were said to impact the way in which children were treated by their peers. Although behavioural changes were noted, these changes appeared for only a small number of participants. This knowledge that cognitive impairments were most commonly noted as challenges associated with cancer indicates a need for future research aimed at exploring current strategies to assist children with cancer overcome these challenges and perhaps determine additional approaches to address these needs.

Social and Peer Related Aspects of the Cancer Experience

Many of the negative implications that the cancer experience has on children can be moderated by positive support systems. Lahteenmaki and colleagues (2002) suggested that supportive peer relationships play an important role in mitigating the negative experiences that result from the cancer and/or its treatment as well as helping the child to readjust to returning to the school environment. Parents who participated in the present study indicated that they were happy for their child to return to school and be able to socialize with his/her peers. Suzuki and Kato (2003) also described the opportunities for social interaction as one of the reasons that parents should encourage their child to return to school.

Despite their desires for their child to return to school, participants indicated that they were nervous about this return and were concerned about how peers would react to

the child. Concerns centered around whether peers would support the child and about how they would respond to the physical changes that the child had experienced. These findings were similar to those of McCarthy and colleagues (1998) who found that children were worried about how their peers would react to their physical changes. In the present study, parents reported that they believed that they were more concerned about this than their child was. With the exception of one participant who reported having problems with his/her peers, participants of the current study reported having positive experiences with peers and did not have many concerns about their peer relationships. Similarly, Bessell (2001) found that participants in her study reported having positive peer relationships. In the outlying case of the current study, where peer relationships were not positive, one parent reported that his/her child missed a fair amount of school as a result of these negative peer interactions. Suzuki and Kato (2003) indicate that some cancer survivors suffer from school phobia. They suggest that fear of being teased and/or rejected by peers can contribute to increased absences. School avoidance as a result of peer interactions was not a significant finding of the current study.

Participants in the current study indicated a variety of changes in the nature of their relationships with peers. Some families noted that although peer support was strong during the earlier phases of the cancer experience, it seemed to decrease as time went on. It appeared that the positive support was present during the initial diagnosis and treatment, yet declined once the treatment had finished.

Cancer survivors in the current study also appeared to take an active role in choosing their friends, often deciding on their own to no longer continue friendships with some people. Participants indicated that the cancer survivors had become more mature

than their same age peers as a result of their experiences, and had therefore felt as though they had less in common with former friends. One participant indicated that his/her child realized who his/her true friends were as a result of this experience. Perhaps as a result of their increased maturity levels, it appeared as though cancer survivors had created supportive social networks outside of the school setting. For many participants, peers from other cancer support groups and organizations were said to be their closest friends.

Overall, participants were satisfied with the level of peer support that was received. Participants described gestures such as visits, class letters, cards and gifts as ways in which they received support from peers during their illness. Support was also judged based on the degree of acceptance that peers demonstrated. In addition to accepting the child and making him/her fit in with the group, peers were also described as being caregivers for the children in the study by being there for them when they were needed. For the majority of the participants in the study, it appeared that children benefited from having the same peer group throughout their cancer experience. For these children, the peer group served as a sense of stability throughout the experience. This finding challenges Fraser's (2003) suggestion that classmates might react negatively to children upon their return, as they may not be aware that it is the same child that they were once friends with. There was one outlier in the current study who coincided with Fraser (2003) in that the parent believed that the negative reaction from peers was a result of their having known the child prior to his/her illness, and not knowing how to respond to the changes that the child had undergone.

Although the majority of participants reported having positive interactions and experiences with peers, there were four participants who described incidents of bullying.

For two of these participants, the bullying was based on changes to the child's physical appearance. This is comparable to findings by Lahteenmaki and colleagues (2002) who also reported that a number of children were bullied as a result of their appearance.

Although participants described incidents of bullying, it did not appear as though bullying was a prominent part of the children's experience and peer relationships, perhaps suggesting that these were discrete incidents. Interestingly, although referring to having supportive peers, the three cancer survivors who participated in the study indicated that they had only a few close friends following their treatment. Although peers were supportive, very few were considered to be close friends. One participant attributed this to the fact that peers did not fully understand his/her circumstances. This person expressed the belief that if peers were more educated about the situation, perhaps he/she would have had a larger peer network.

In the present study, participants placed an overwhelming emphasis on the importance of educating peers about cancer and about each child's individual situation. Literature indicates that children may have misconceptions regarding cancer and other chronic illnesses (Prevatt et al., 2000; Sigelman et al., 1993). Findings from the current study correspond with the literature as participants described a number of misconceptions that peers had regarding the child's illness. Misconceptions included peers believing that a child's hair had regrown much faster than was actually true, as well as fears of catching cancer from a child. Prevatt and colleagues (2000) also indicate that fear of contagion is a major reason why children with cancer are avoided by their peers.

Participants indicated the importance of educating peers about cancer as a way to increase acceptance. Negative reactions from peers were attributed to a lack of

understanding and knowledge, therefore it was believed that the more aware peers were of a child's circumstances, the less afraid and more accepting they would become. This suggestion by participants is similar to that of Goddell (1984) in which it was assumed that knowledge would overcome the fear that triggers negative responses from peers towards a child who had cancer. Participants in the current study chose to educate peers though having presentations done in the child's class, which were designed to teach peers about the child's condition and promote positive interactions and acceptance.

Peer relationships were generally referred to as being positive. Bullying appeared to be a problem experienced by some participants, indicating a demand for future research which explores this bullying and ways in which it can be prevented. Participants highlighted the importance of educating peers about cancer as a means to avoid misconceptions and negative attitudes towards children who have cancer. The various strategies and interventions used to communicate this information could be examined in order to compare their effectiveness and determine the most successful approach to ameliorate peer relationships.

Perceived Support

In addition to describing support from peers, participants spoke of seeking out and receiving academic support through frequent meetings with school personnel. During the initial return to school, participants reported meeting with a variety of school personnel, however meeting with teachers appeared to be the most common form of communicating about their child's circumstances. Participants believed that speaking directly to the teachers was the most effective way to ensure that their child was receiving the support that he/she required. Parents described recruiting the assistance of members of their

child's health team during the meetings with school staff in order to attest to the child's needs. This is similar to Cabat and Shafer's (2002) description of the collaboration of parents, school staff, medical professionals and children in the re-entry program for children, however the involvement of medical professionals in the current study appeared to be less formal than that described by Cabat and Shafer (2002). Although Cabat and Shafer (2002) did not indicate parents' specific reasons for having the health care team present, participants of the current study indicated that they often brought them in when they were not successful in advocating for support services on their own. Despite these efforts, the meetings were not always effective in securing supports for the children represented in this study. When describing the accessibility of resources, participants indicated that the process was more difficult in high school than in elementary school. Reasons for this increased difficulty included larger class sizes, a greater emphasis on student independence and students having more teachers, with a different teacher for each subject taught in high school.

In all levels of schooling, funding and budget allocation were viewed as barriers to support. Participants indicated that the allocation of resources for their child was dependent on budgets. A number of participants felt as though there was not enough money allocated in order to provide them with the support that they needed. There was a concern amongst participants that economic changes and ongoing budget cutbacks would exacerbate their existing challenges.

Participants described the measures that they had taken to seek out support for their child. One common method was to have an assessment and report done by either the child's oncologist or a neuropsychologist to describe the child's circumstances and attest

to the academic challenges that the child was experiencing. Parents felt that having documentation to verify these challenges was generally helpful in dealing with the schools. The reports were also used to help develop the child's IEP. Although the majority of participants felt that these reports were helpful in attaining support, two participants specified that the reports were not effective for them.

Information that was included in the reports was also used in some cases for the purposes of identifying children with an exceptionality. The Ministry of Education defines categories of exceptionality for which special education programs must be provided (Bennett et al., 2008; Ministry of Education, 2001). Participants of the study explained their frustration with the fact that childhood cancer does not fit into these categories, therefore making it more challenging for parents to petition for the support that their child required. Bennett and colleagues (2008) described the debate over whether the categories are too exclusive and recognized that the official categories and definitions of exceptionality are key factors in determining whether students will be identified and receive special education resources. Participants in the study also shared their view that without formal identification their child was not guaranteed to receive these resources, necessitating more work from the parents in advocating for support. As children who have cancer are a very heterogeneous group, it is difficult to fit them into any one category of exceptionality. This is similar to Bennett and colleagues' (2008) description of the difficulty that all children face when being identified since they may fit into a number of different categories, while at the same time falling through the cracks in definitions. As a result of the difficulty in placing students who have cancer into a specific category, participants in the current study described their desire to have the

children recognized under a medically fragile category. Participants felt that by having this identification, their child's academic needs would be met.

In addition to discussing the infrastructure in schools to arrange support for the children, effective supports and supports that were not available, as well the processes families used to access or advocate for supports, were also examined. When discussing support services that families received while their child was in treatment, a few participants mentioned hospital teachers. Only one participant spoke of his/her child receiving educational support in the hospital, however this was support that was arranged by the school rather than hospital based teaching. Two other participants mentioned hospital teachers, but stated that they had not received this support. This suggests that perhaps this was not a significant resource for families, or that this support was not made available to them. More research into the allocation of this support and its availability would be necessary to determine why only one participant received this.

Although not many families received hospital teaching, a number of participants spoke of the benefits of tutoring. Only two families described having the assistance of a tutor for their child. One family had their tutor funded through the school board, while the other had to seek out private tutoring. Lahteenmaki and colleagues (2002) described the benefits of tutoring, explaining that tutoring, along with special education services, could help to enhance the educational achievement of children who have cancer. They recommended that more funding be allocated for tutoring children who have chronic illnesses in order to optimize their academic potential. Both of the families who received tutoring spoke of the benefits that their child received as a result of having this support. One participant acknowledged that the tutoring helped to bring his/her child to the

appropriate academic level, while another parent described the increased confidence that his/her child had as a result of this support. Considering the suggestion by Lahteenmaki and colleagues (2002) and the results described by participants, one might assume that tutoring would be a valuable support in facilitating the academic achievement and success of children who have cancer.

An additional source of academic support for the children who had cancer was home instruction while they were involved in treatment. The overall consensus from participants was that this was a valuable resource, however the process of putting it in place acted as a barrier to receiving the support when it was most needed. Participants described the conditions that had to be met in order for a child to qualify for home instruction. The amount of time that a child was away from school was one of these conditions and participants discussed their efforts to advocate for children to receive home instruction throughout the entire time that they were involved in treatment, rather than just during their initial hospitalization. The reason behind this is to allow children to attend school when they were well enough, but still have the consistent support from a home instructor for the days when they are not able to attend school. With the exception of one participant who was not satisfied with the support that he/she received from the home instruction teacher, participants were happy with the quality of support that they received, however they felt that it was not enough. They wanted the support to be more accessible and consistent throughout the illness experience.

In order for families to facilitate a smooth reintegration into the school environment, re-entry presentations and programs are often put in place for the children when they are ready to return to school. Cabat and Shafer (2002) describe school re-entry

programs as involving the collaboration of parents, school staff, medical professionals and the children themselves. Although participants discussed having medical staff present when meeting with school staff, the re-entry presentations that they described did not include medical staff. This differs from Lightfoot and colleagues' (1999) finding where students reported having health professionals visit their school to speak to their peers. Participants in the current study did describe having the help of a member of their regional parent support group, from which participants were recruited, who took the lead during the presentation. For these children, the re-entry presentation consisted of having the member of the support group tell the child's classmates, and often classmates of siblings as well, about cancer and what the child was experiencing. Both the child who had cancer and his/her parent(s) were present during the presentations that were described. Literature discussing re-entry programs for children who have cancer also explain that the child who has cancer is given the option to participate in the presentation and tell their peers about their experiences (Madan-Swain et al., 1999; McCarthy et al., 1998; Prevatt et al., 2000).

When describing school re-entry programs, Madan-Swain and colleagues (1999) acknowledge the variation among different programs, however they also illustrate a series of phases through which the process occurs. The description of the school re-entry program/presentation from participants of the current study appeared to be much less formal and scripted than the programs described in the literature. The process depicted by participants represented the third phase of the re-entry program described by Prevatt and colleagues (2000), which included peer education programs. Participants in the current study reported that they were satisfied with the presentation that was done for their child

and that overall, peers were very accepting of the child following these presentations.

Participants indicated the value that they attributed to this form of support by describing their belief that the more children and teachers are educated, the more accommodating and accepting they will be.

Educating peers was an important component of the re-entry program for families who participated in the study. Along with educating peers came the emphasis that participants placed on educating the educators. Parents felt that they had to consistently remind school staff that their child was still sick, despite the fact that the child may have completed the initial phases of his/her treatment. Participants wanted to ensure that staff were aware of their child's fragile health conditions in order for them to be cautious of illnesses within the school, as well as to provide the necessary accommodations while the child was in school. Participants believed that educators should be provided with resources and education in order to help them understand the child's needs. The benefit of educating educators has been illustrated by Prevatt and colleagues (2000) who described personnel workshops that focus on educating school staff about the treatment and side effects of childhood cancer. They found that the workshops often resulted in school personnel being more confident in their ability to educate a child who has cancer. Similarly, participants of the current study believed that, if given the appropriate education and resources, teachers would be more capable and willing to help their child.

Perhaps as a result of a lack of education, participants introduced the term "invisible disability" to describe their child's experience once the treatment was completed. Participants believed that because the disabilities that the children experienced did not have physical, visible signs, teachers were reluctant to provide extra

support and assistance and insisted on treating the child in the same manner as “normal” students. Mukherjee and colleagues (2000) also found that the degree to which a child’s illness and its symptoms were visible was seen to influence teachers’ willingness to believe that a child was ill. Participants explained that their child’s “invisible disability” served as an additional barrier to receiving support.

When discussing participants’ overall experiences throughout their child’s journey, parents suggested that their experiences were very dependent on the school. It appeared that parents who described their child’s school climate in positive terms had a better experience than those who felt that their school climate was not supportive and positive. All but one participant described an overall sense of support and acceptance from their child’s school, suggesting a positive atmosphere. Many participants spoke of establishing a relationship with the school staff. These positive relationships left participants feeling more comfortable with sending their child to school. In describing ways in which the school climate was not supportive, one parent indicated feeling intimidated by the school staff. This parent also described the way in which the school seemed to be supportive during the child’s initial treatment, yet decreased their support once the treatment had ended. The most supportive schools were often those where staff had experience with another student who had cancer as well as those where staff had established a relationship with the family.

One way that schools were seen to be supportive was by providing students with various individualized accommodations and modifications in order to help them succeed academically. When discussing the various accommodations that students received, it became apparent that children did not wish to have accommodations that were visible.

They often chose not to use assistive devices or be removed from their classroom as these things made them appear different from their peers. Parents described their efforts to have necessary accommodations available for their children while also respecting their wishes to be as inconspicuous as possible.

When working with the school to establish support, participants indicated that the principal was the most important person in the school in terms of establishing and maintaining support for the child. This interpretation by parents is in agreement with the Ministry of Education's (2001) description of the principal of each school being the one to ensure that special education programs are delivered effectively for students. Participants indicated that when their child's school had a change in principal, their experience of receiving support also changed. Parents expressed their frustration with the inconsistency that this caused and indicated that this often resulted in them having to spend more time explaining their child's needs. It was suggested that there should be a resource at the board level to communicate needs and establish resources in order to ensure consistency in the support that families receive. A similar liaison position for the coordination of resources, as well as the delivery of information, to facilitate consistency among school staff was also suggested in current research (Eiser, 2004; Harris, 2009; Mukherjee et al., 2000). The varying degrees of support that families received from Principals were also discussed.

While principals are responsible for providing special education resources, participants indicated that teachers were the ones with whom they interacted the most. As a result of this constant interaction, a family's experience of their child being in school was dependent on the teacher. This finding is consistent with Bessell's (2001) and

Lightfoot and colleagues' (1999) descriptions of teachers being the most important people in creating a successful school environment for the child and impacting the child's experience. Participants indicated that the child's feelings about being in school were dependent on the degree to which the teachers showed concern for the child. Lightfoot and colleagues (1999) also stress the importance of having a teacher who understands the child's situation in shaping the child's experience.

Incidents where participants felt that teachers were not supportive were described. Participants perceived teachers to be non-supportive when they did not appear to understand the child's needs and were unwilling to listen to parents' concerns. Literature suggests that support from teachers can vary within a given school. The level of awareness and understanding of the child's condition, as well as the attitudes that teachers possess, all influence the degree of support that they provide (Madan-Swain et al., 1999; Mukherjee et al., 2000). Participants also described incidents where teachers did not comply with the child's IEP and were not providing the accommodations and modifications that the child required. Similarly, Bessell (2001) also indicates that participants who reported poor relationships with their teachers listed a lack of appropriate accommodations as a reason for this.

Although participants described the variation in support that they received from teachers, it was evident that the majority of the children's teachers were supportive. Teachers who developed relationships with the child and family and maintained consistent communication with the family were seen as helpful. Similar to findings by Lightfoot and colleagues (2001), participants felt that teachers who understood the child's situation and needs played a key role in supporting the child. One interesting finding by

Bessell (2001) was that most teachers who were perceived as helpful had their own experiences with cancer. A number of participants who described positive support from school staff also acknowledged that their child's school had experience with other students who had cancer as well.

In addition to receiving support from teachers in the classroom, parents of two children in the current study reported having EA support for their children. These participants explained that EAs provided academic and physical support. For those who did receive this support, parents regarded it as effective, however one family shared their frustration with the fact that his/her child received shared support, and therefore the support received was often inconsistent.

Participants referred to resources that they perceived as helpful and supportive, which were separate from the school. One of these resources was the Interlink Nurse, whom participants explained helped connect them to other support agencies. According to the Pediatric Oncology Group of Ontario (POGO) (2011), Interlink Nurses facilitate access to the necessary supports that children and their families require during their illness experience both within the hospital and community. This nursing position is funded by the Ministry of Health and Long-Term Care and operates out of the major pediatric cancer treatment centres throughout the province. Other medically related resources that participants received included Physiotherapy and Occupational Therapy. In addition to medically related resources, participants indicated that they received assistance from organizations related to supporting those who are affected by cancer. Examples that were mentioned by participants included POGO, various camps for children and siblings affected by cancer and other cancer support groups. Support from

members of participants' church communities, as well as assistance from family members and friends were also described as valuable resources for participants.

When offering suggestions for other families who may have to undergo a similar cancer experience, participants emphasized the need to ask for help. They recommended that new families ask for simple assistance such as childcare, or to have meals made for them. Similarly, participants also emphasized that they were able and willing to provide support to other families through their support group.

The general needs indicated by participants centered on the need for more consistency in the support that families receive. Future studies might seek to further explore families' views on having their child be identified under a category of exceptionality as a means of securing resources. An exploration of the potential benefits and disadvantages associated with identification would also be beneficial. Families discussed issues related to the infrastructure in schools that was necessary to support their child. Included in these discussions were descriptions of effective supports and supports that were not available as well the processes families used to access or advocate for supports. It would be interesting to determine whether having liaison or advocate position, whose job would be to communicate the child's needs between the family, school and medical team would enhance families perceptions of the support that they receive.

Siblings

The impact that the cancer experience has on one's family could not be adequately discussed without considering the way in which healthy siblings of a child who has cancer are affected. Participants in the current study described siblings as the

“forgotten patients”, as often they are overlooked when studying the experience. One common finding was that siblings of children who have cancer often found their routines and special events to be interrupted. Murray (2000) described the interruption of normal family life that the cancer experience imposes on all family members. Subsequent to this notion, Eiser (2004) indicated the possibility that these disruptions result in emotional problems in siblings of children who have cancer. Participants in the current study indicated that their healthy children often expressed anger and jealousy towards their sibling who had cancer, and some families attributed these emotions to the division of parental attention.

Not all sibling reactions are negative. Parents also described siblings displaying increased empathy and sympathy, which is similar to findings that siblings of children who have cancer often have an enhanced sense of maturity and compassion (Eiser, 2004; Murray 2002). Woodgate (2006) found that, overall, family bonds were strengthened as a result of the cancer experience. Participants of the current study indicated that the degree to which bonds were strengthened varied, with three participants describing that their children had become much closer than they were prior to the cancer experience, and two participants indicating that the cancer experience had caused a rift between their children. Participants also explained that their healthy children often took on a mothering role, taking on extra responsibilities within the house and helping their sibling who had cancer. This finding is comparable to Eiser’s (2004) and Woodgate’s (2006) discussions of siblings assuming additional chores and responsibilities.

Issues relating to support for siblings included the nature of the siblings’ relationships with their peers, as well as other support services that are available for

siblings of children who have cancer. When examining their peer relationships, the majority of the siblings represented in this study were said to have supportive peers. Participants indicated a need for more support services for siblings. Programs provided by the participants' support group as well as camps for children and families of children who have cancer were described as valuable resources for siblings. Despite these, participants indicated that there were not enough resources that are designed specifically for the healthy siblings of children who have cancer. Parents shared their wish that the variety and availability of sibling support resources be increased in order to help address the needs of siblings. This suggestion is similar to Murray's (2002) suggestion that social support be available for siblings of children who have cancer as a way to help minimize the impact that the illness has on their own lives. Research into the availability and accessibility of support sources for siblings as well as their effectiveness on minimizing the implications that the cancer experience has on healthy siblings should be further explored.

Advocating

Participants described their need to consistently advocate for their child. Participants indicated that this advocating took the form of frequent meetings with school staff in order to have them understand the child's needs and to provide the necessary accommodations, modifications and resources to meet those needs. Patterson and colleagues (2004) also acknowledge parents having to advocate for their child at school and indicate that this could contribute to parents' stress levels. Participants in the study also spoke of the amount of time that was required to advocate for their child and acknowledged that most parents do not have the time to meet with the schools regularly.

Advocating was a way in which families accessed support, however the amount of time that this required also served as a barrier to receiving support, as not all families are able to spend the time doing so.

When speaking of the process of advocating, participants often referred to it as a “fight”. Terms such as “ongoing battle” and “hold me back” were also used by parents when describing their interactions with school staff. This language suggests that parents viewed the need to advocate as a barrier to receiving the support that their child needed. One participant stated, “We’re fighting at a time that we shouldn’t have to be” (Participant 11). Taking into consideration the demands placed on families throughout the cancer experience, participants felt as though the fight to ensure that their child was receiving support was unnecessary and only added to the stress of the experience.

Normal

In the discussion about the ways in which children and families were affected by the cancer experience, it appeared as though all families were working to have their child return to a state of normalcy. According to Bessell (2001), cancer interrupts and changes the regular routines and lives of children who are diagnosed. Participants consistently referred to having their child return to being a “normal” kid, with a “normal” routine. Literature indicates that returning to school following cancer diagnosis and/or treatment is a major component of a child returning to their normal routines (McCarthy et al., 1998; Sullivan et al., 2001). This finding was also present in the current study as parents described their views on school being a normal environment for children. Being well enough to attend school was an indicator for participants that their child’s life was returning to normal. Although parents expressed their concerns about their child’s health

while being in the school environment, they all indicated that their desire for their child to be in school and to interact with his/her peers was more important.

Experiences of Others

Participants often compared their own experiences to those of other families that they associated with. Although participants described their personal hardships as a result of their child having cancer, many also referred to the ways in which they were fortunate in comparison to other families.

Limitations and Suggestions for Future Research

This study provided a description of the lived experience of families' lives as a child who has cancer re-enters the school system. Although the study has created insight into this experience, it is important to acknowledge the limitations that exist.

Perspectives and testimonies.

In exploring the children's and families' experiences throughout the school re-entry process, efforts were made to gain an understanding of the lived experience of all members of the family, including children of various ages who are childhood cancer survivors and their siblings. A major limitation is the small number of childhood cancer survivors who participated and the fact that in all cases, the experience of returning to school happened at least two years prior to the interviews. Additionally, it was not possible to interview siblings directly, therefore parent perspectives are the only source of information regarding sibling experiences. This is a limitation as parents are only speaking of their own perceptions of the siblings' experience and how they themselves view the phenomenon. Ideally, it would have been best to interview siblings in addition

to the parents, as was the case with the childhood cancer survivors, to allow for the different perspectives to be compared or to support and complement each other.

As in the research done by Woodgate (2006), although parents were aware that their healthy children experienced feelings of sadness, they were not aware of the extent to which they felt this way. Rather, they listed a number of other feelings such as jealousy, fear and loneliness as those that were most commonly experienced by the healthy sibling. This discrepancy between parent perceptions and siblings' actual feelings indicates the limitation in a study that discusses the sibling experience without actually consulting with the siblings and highlights the need to have the people being studied, in this case, the siblings, play an active role in the research process (Woodgate 2006). It is recommended that future studies in this field speak directly to the siblings of children who have, or have had, cancer in order to obtain a more accurate account of the ways in which they experience this phenomenon.

Similar to the limited reliability of the sibling perspective, having families describe their interactions with, and perceived support received from teachers and other school staff without consulting with school staff themselves also limits the validity of the results. The focus of this study was on the lived experience of the children and their families, however the perspective of the educators and how they contribute to this experience would be interesting. Although the majority of the participants agreed that their child's teachers were supportive, incidents in which participants felt that they were not receiving adequate support were described as well. As support is perceived in the mind of those receiving it, it is possible that teachers were trying to support the families, despite not been seen as supportive due to any number of factors. Similar to studies by

McCarthy and colleagues, (1998) and Mukherjee and colleagues (2000), which included teachers, when considering the degree of support received from school staff, future studies might incorporate a form of teacher evaluation or perhaps recruit the participation of teachers to describe their experiences in conjunction with the experiences of the children and families. Doing so would provide insight into the entire process of both delivering and receiving support and can offer information as to how effective this support is in facilitating a positive school experience.

Having gathered participants from only one pre-existing group, the results of this study cannot be generalized. It may be that the experiences of this group are unusual and that they may have all experienced the re-entry process in a way that is similar to one another, yet different from most other families. Families from other geographic regions may have received treatment and/or resources, which may have been different from what was received by the participants of this study. These differences could potentially influence the way in which families experience the return to school as a result of the various levels of support received. Future studies should include participants from different regions or different support networks in order to determine whether their experiences are similar.

Participation in the study was voluntary, creating the possibility that participants who were not in a stage of their experience that would afford them the time to participate avoided doing so. Many of the participants spoke of generally having positive experiences. It is possible that it is a result of such positive experiences that these families agreed to take the time to participate in the study. Families who chose not to participate in the study may not have had such positive experiences, and possibly had other demands

relating to their experience to attend to, rather than participate in the study. They may have been working through the stresses of these experiences and, therefore, not have the time, or been keen to contribute to the study. The study was designed in such a way as to limit imposition on the lives and routines of participants by having the focus group take place during a regularly scheduled meeting of the parent support group and interviews conducted either on the phone or a location of the participants' choice.

Research design.

From start to finish, aspects of this study differed from the original design.

With regard to the focus group, it would have been ideal to have more focus groups with fewer people in each group, rather than having one focus group with such a large number of participants. While the composition of the focus group in this study was less than ideal, it remained this way in order to respect the dynamics of the intact group.

Participants consisted of a previously formed group that gathers at a particular time each month. It was decided that it would be best to arrange the focus group during a regularly scheduled meeting time in order to accommodate the participants. To conduct separate focus groups might have interfered with the participants' need to seek support from the group in that more than one of their meetings would be interrupted, and if arranged at an alternative time, it may have also interfered with their already busy schedules as a result of their child's health circumstances. Not all participants who attended the focus group contributed to the discussion. This may have been different had the group size been smaller, allowing more opportunities for participants to share their experiences. As the group coordinator was not able to predict how many participants would attend the meeting, it was unknown that there would be such a large number of participants. Future

studies might look at coordinating smaller focus groups at times and locations that might be convenient for participants.

The large number of participants in the focus group also created a limitation in the distribution of the demographic questionnaire. Although efforts were made to wrap up the discussion, participants continued to share their experiences, and the children, whose own program that coincided with the parent meetings had ended, interrupted the meeting. As a result of this, the questionnaire was not distributed at the time of the focus group. The questionnaire was later included in the interviews, yet data were not available for all children represented in the study. As a result of this, the questionnaire was not used in the analysis section of the study.

The questionnaire had been designed to gain an understanding of the differences in factors such as the child's age, diagnosis and stage of their illness. This information would have helped to understand similarities and differences in participants experiences based on their diagnosis and the resources that were available to them at the time of their re-entry. Since participants were recruited through a support group, rather than a treatment centre, they represented a cross sectional sample at a variety of stages within the illness trajectory, ranging from being currently on treatment, in remission, and being cured for upwards of 20 years. Although this does allow for a broad picture of the experiences, the results cannot be generalized, as the treatment received, policies and resources available to these families differed as a result of the time that had elapsed between their experiences. Future studies might work with participants who are all at the same stage of the experience in order to obtain a more comprehensive representation. Similarly, it would be interesting to compare the experiences of these groups

longitudinally at various stages to gain a sense of how their experiences and perceptions of support change.

Although the process of data analysis followed detailed guidelines (Braun & Clarke, 2006; Creswell, 2003; Fereday & Muir-Cochrane, 2006), it is possible that the interpretations made from the data are not completely accurate from the perspective of the participants. Although a member checking summary letter to be sent to participants was intended, the delays in the completion of this project resulted in an extended period of time between the time the data collection and data analysis phases. As such, the member checking phase was omitted from the project. Having participants confirm that the results were an accurate representation of their experiences would have helped to ensure the validity of the results. Measures to ensure the validity of research findings are an important element in qualitative research, and as such, should be considered in future research studies.

Summary

Although this study does not represent the experiences of all families of children with cancer, the results do provide interesting insight into how these families experience their child being in school following diagnosis and/or treatment for childhood cancer. Participants in this study represented a diverse group and generally reported having similar experiences despite variations in the types of diagnoses, treatment and time since diagnosis. Generally, participants felt that they had been fortunate in their experiences, noting that other families had faced greater challenges. Specific needs indicated by participants included the need for greater consistency in resource allocation and school policy in order to ensure that students were being supported. Participants shared examples

of the ways in which they felt that they had to consistently advocate in order for their child to receive the support and resources that were necessary. Participants also indicated the need for educating both the educators and peers, as they often found that children with cancer were better received by teachers and peers who were more informed about the child's circumstances. In addition to providing resources for the child with cancer, participants also indicated that there is a shortage of resources available to support healthy siblings and the need for the development of more resources to meet their needs.

These results indicate the need for more research to be done in areas concerning the delivery of support and the allocation of resources for all family members of children who have cancer. It is important that school personnel understand the circumstances of these families and work with parents to ensure the consistent delivery of necessary resources. In order to develop a complete understanding of the families' experiences, it is recommended that all members of the family be included in the research process. It is imperative that more research be done to develop a better understanding of these needs. Research that focuses on the specific resources desired and delivered, as well as the infrastructure through which families need to navigate, would also be beneficial in creating an understanding of this experience. Through exploring this phenomenon in greater depth, it is hoped that the implications that cancer and/or its treatment create for families can be minimized, thus enhancing their quality of life after survival.

Conclusion

The key results of the study indicate that participants perceived cancer as abnormal and consistently strived to have their lives return to normal. Children experienced a significant degree of change as a result of the disease and/or treatment. The

most significant of these changes were cognitive and physical. Regardless of the implications that the disease and/or its treatment posed, participants in the study stressed the children's wish to not appear different from their peers. Families sought ways to ensure that children received necessary support while minimizing the visibility of these resources. Children often experienced cognitive impairments that tended to be manifested in the school setting as they impacted the children's academic achievement in math and language.

Similarly, participants described the impact that the physical changes resulting from their illness had on children's peer relationships. Participants explained that peers had a hard time relating to the children as a result of changes in their appearance which resulted in strains in their relationships. Although most participants reported that the children had positive peer relationships, issues such as bullying did exist and were attributed to peers' lack of understanding of the children's circumstances. Participants emphasized the need to educate peers about cancer as a way to increase acceptance and promote positive peer relationships.

In addition to educating peers, participants also stressed the need to educate school staff. The notion of cancer being an "invisible disability" emerged through this study. The children with cancer were described as not having physical, visible signs of their disabilities and the challenges that resulted from their disease and/or treatment. Along with the restrictive definitions of exceptionalities outlined by the Ministry of Education, this "invisible disability" appeared to be a barrier to families receiving necessary educational resources.

In working with the school staff, participants indicated that the school principal is the key figure in terms of establishing and maintaining structural support for children returning to school after treatment. However, it is the teacher, with whom the children interact on a daily basis, who is crucial in shaping the families' experience of school re-entry. Fortunately, participants reported that the majority of the children's teachers had been supportive.

Participants described their need to consistently advocate for their child. The process of advocating was often referred to as a "fight" with school officials in order to receive individualized supports and this was also seen as a barrier to receiving the resources that their child needed. The major recommendation that participants had was that allocation and delivery of support services and resources be more consistent.

Resources and supports for siblings were reported to be insufficient as well, and participants indicated the need for more resources within the school and community to be developed specifically for the healthy siblings of children who have cancer. Major findings relating to siblings of children who have cancer include the notion of siblings as "forgotten patients" as a result of the difference in attention being paid to them and their ill sibling. Participants acknowledged the interruptions in the siblings' routines as a result of having a sibling who had cancer and explained that siblings had expressed anger and jealousy as a result. Alternatively, participants also indicated that healthy siblings exhibited increased empathy and sympathy and often took on caregiver roles to help their ill sibling.

Children are increasingly surviving their battles with cancer and are now faced with the challenge of restoring their lives and routines to normal upon the completion of

their treatment. These findings indicate the immense struggle that children who have cancer and their families face in this process and outline the needs that families express in achieving these goals.

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Appendix A: Letter of Invitation

February 2009

Title of Study: Back to School, Back to Normal? Understanding the Experiences of Childhood Cancer Survivors Throughout the School Re-Entry Process

Principal Investigator: Marlene Oleiro, MA Candidate, Department of Child and Youth Studies, Brock University

Faculty Supervisor: Jan Frijters, Associate Professor, Department of Child and Youth Studies, Brock University

I, Marlene Oleiro, Graduate Student from the Department of Child and Youth Studies, Brock University, invite you to participate in a research project entitled Back to School, Back to Normal? Understanding the Experiences of Childhood Cancer Survivors Throughout the School Re-Entry Process.

The purpose of this research project is to develop an understanding of what it is like for children with cancer to be in school. More specifically, the goal of the study is to learn about the school re-entry process and how children and their families are affected by it. This will involve an in depth look at a variety of factors that contribute to this experience such as social, emotional, physical and academic issues.

The expected duration of your participation is approximately 90 minutes. Should you wish to participate in a follow up interview, an additional hour of your time will be required.

This research should benefit the community by contributing to a growing body of knowledge regarding the education of children who have cancer. By learning about this experience and how individuals are affected we can have a better idea of what other children with cancer and their families can expect when they return to school.

Permission for this study to take place during the Candlelighters - Simcoe meeting has been granted by Ms. Barb Johnson. This is a single-site project.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me.

Thank you

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Dr. Jan Frijters
Associate Professor
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This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # REB 08-171)

Appendix B: Parent Consent Form

Date: **February 2009**

Project Title: **Back to School, Back to Normal? Understanding the Experiences of Childhood Cancer Survivors Throughout the School Re-Entry Process**

Principal Investigator:
Marlene Oleiro, MA Candidate
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INVITATION

You are invited to participate in a study that involves research. The purpose of this study is to develop an understanding of what it is like for children with cancer to be in school. More specifically, the goal of the study is to learn about the school re-entry process and how children and their families are affected by it. This will involve an in depth look at a variety of factors that contribute to this experience such as social, emotional, physical and academic issues.

WHAT'S INVOLVED

As a participant, you will be asked to participate in a focus group with other parents of children who either have or have survived cancer. The goal of the focus group will be to discuss your family's experiences throughout your child's return to school. At the beginning of the focus group you will be asked to complete a form asking questions about your child's history. Following the completion of the forms, there will be a number of questions asked to the group and you will be given an opportunity to share your story and hear the stories of the other participants. The focus group will be video taped in order to ensure that when the conversation is transcribed, the information is correct. The use of video recording will also help to ensure that statements are recorded as being said by the proper individuals. Participation will take approximately 90 minutes of your time.

With your permission, I would like to contact you again in one month to ask you to participate in a follow-up interview. This interview will take place at a mutually agreed upon location, or over the telephone if you prefer. The interview will involve me asking you a set of questions similar to those asked in the focus group. Interviews will be tape recorded to ensure that the information shared is recorded correctly. Your participation in the interviews will take approximately one hour of your time. If you wish to be contacted to participate in the interview portion of this study, please complete the contact information section below.

Additionally, with your permission, I would like to meet and have an interview with your child/children (your child who has cancer and/or his/her siblings) at around the same time

as your interview to discuss their experiences as well. This interview will take place at a mutually agreed upon location, or over the telephone if you prefer. The interview will involve me asking your child/children a set of questions similar to those asked in the focus group, but more focused on their own experiences. Interviews will be tape recorded to ensure that the information shared is recorded correctly. Participation in the interviews will take approximately one hour of your child's time. If you wish to be contacted to have your child participate in the interview portion of this study, please indicate this in the contact information section below.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include the contribution to a growing body of knowledge regarding the education of children who have cancer. By learning about this experience and how individuals are affected we can have a better idea of what other children with cancer and their families can expect when they return to school. There also may be risks associated with participation, in that you or your child/children may experience some discomfort or emotional stress recalling or discussing feelings and experiences. There are no known or anticipated physical risks associated with participation in this study.

CONFIDENTIALITY

Focus Group

Due to the nature of the focus group, confidentiality cannot be guaranteed. All information you provide during the session will be heard by others in the group. Your name will not appear in any thesis or report resulting from this study; however, with your permission, anonymous quotations may be used. Given the format of this session, we ask you to respect your fellow participants by keeping all information that identifies or could potentially identify a participant and/or his/her comments confidential. All data resulting from the focus group will be treated as confidential.

Interviews

The information you and/or your child/children provide will be kept confidential. Your names will not appear in any thesis or report resulting from this study; however, with your permission, anonymous quotations may be used.

Data collected from this study will be stored in a locked filing cabinet. Data will be kept for approximately eight months, after which time any paper copies will be shredded and all electronic data sources will be destroyed. Access to this data will be restricted to myself and my faculty supervisor, Dr. Jan Frijters.

****Please note that confidentiality will be broken in the event of the disclosure of abuse, threat of harm to self or others, or information required in a subpoena****

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study.

Further, you may decide to withdraw from this study at any time and may do so without any penalty. You can withdraw before participating, while participating and after you

have participated. The deadline to withdraw your data from the study will be six months after the date of your interview.

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available once the study has been completed. If you wish to receive feedback from this study, please indicate below and provide your contact information.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (File Number REB 08-171). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

Focus Group Participation

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Interview Participation

I would like to be contacted to participate in a follow-up interview. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Telephone number: (____) _____

Email address (optional): _____

Child Interview Participation

I agree to allow my child to participate in an interview described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Telephone number: (____)_____

Email address (optional): _____

Feedback

If you wish to receive feedback following the completion of the study, please provide the information requested below:

Mailing Address: _____

or

Email Address: _____

Appendix C: Focus Group Questions

- What were your initial thoughts about your child returning to school? Can you describe any worries or negative feelings that you might have had? Can you describe any positive feelings that you might have had?
- What are your thoughts about the services available to help guide you through this experience? How easily accessible were they? How could they be improved?
- Please tell me about the role of the school staff. Did you find that they were helpful? Why/why not?
- How do you feel about your child's teacher and principal?
- What could be done on the school's end to make this experience better for you now, or for other families who will go through this experience in the future?
- In the time that your child was away from school did you have access to tutors or home schooling?
- Did your child maintain contact with peers and/or school personnel?
- Some people have said that children with chronic illness are absent from school much more often than children without chronic illness. I'm sure that many absences are due to medical appointments, but apart from that, does/did your child miss a lot of school? What are some of the reasons that your child misses/missed school?
- It is said that many parents are afraid of sending their child back to school following diagnosis. Some of the reasons have been fears of infection and fears of social isolation. Did you experience any fear of having your child return to school? Can you describe how you felt?
- How would you describe your child's social life? Does he/she have a good peer group? Are the other children generally accepting of your child, or do you feel as though your child is bullied or an outcast?
- If you have any other school aged children, can you tell me how you think they have been affected by your child's return to school?
 - Have they had to take on a caregiver role?
 - Do other children ask them a lot of questions?
 - Have they encountered any problems with other children as a result of their sibling's illness?

- What would you say to parents who will soon be going through the experience of having their child return to school? Any advice or words of wisdom?
- What are some things that you found especially helpful throughout the process?
- What are some things that you found particularly frustrating or difficult?

Appendix D: Parent Interview Questions

General Questions:

- Can you describe your initial feelings regarding your child's return to school? Can you give me examples of some of these feelings?
- Now that your child is back in school, do you still have the same feelings and concerns?

Cognitive/Academic Questions:

- Some people say that cancer survivors are at risk for cognitive difficulties as a result of their treatment. Has your child experienced any of these difficulties? Can you tell me about them?
- Can you tell me what effect you think these difficulties have had on your child's experiences at school?
- Relative to your child's peers, where do you think your child stands in terms of academic progress?
- Does your child seem to exhibit any concerns regarding his/her academic progress? Can you give me an example?
- There are cases where childhood cancer survivors may not exhibit any cognitive changes, yet there seem to be a number of behavioural changes. Have you noticed or been made aware of any changes in your child? Can you describe them to me?

Social Issues:

- Some people say that cancer survivors experience a number of social issues regarding their peers. Some state this is a result of misconceptions among peers, or anxiety relating to physical changes in the child. To our knowledge, can you tell me about your child's peer relationships and interactions?
- Have there been any peer related problems? Can you tell me about them?
- Has your child ever expressed concern about peer rejection or other peer related issues? Can you give me an example?
- Would you describe your child's peers as supportive? How so?
- Are you aware of any special gestures or favours that your child's peers have done to help him/her out, or to make him/her feel better or special? Can you tell me about this?
- Does your child interact with the same group of children that he/she interacted with before being diagnosed?
- How does your child interact with his/her peers the most?
 - Do they interact mostly at recess?
 - Are there home visits or do they get together on weekends?
 - Do they talk on the phone or use the Internet?
- Some people think that children's knowledge regarding disease and illness influences how they respond to an individual who is ill. How prepared do you think that your child's peers were for his/her return to school?

Support Issues:

- Can you tell me about any programs or help that your family received regarding your child's school re-entry?
- What processes, if any, were used for teaching the school and students about your child's illness?
- In your opinion, what are some of the positive aspects of this process?
- Can you tell me about some aspects of this process that you feel need improvement?
- Did your child receive any academic support? For example, homebound instruction, hospital teaching, tutors, special education. Can you describe these to me?
- How effective did you find them?
- Do you find that the support services were/are consistent?
- How would you describe the communication between the hospital and your child's school? Do you think it is adequate?
- Could something be done to make any support services more efficient or beneficial for you and your family? Can you explain?
- How do you feel about your child's teacher/s?
 - Are they helpful? Can you give me an example?
 - Are they supportive? Can you give me an example?
 - Are they sensitive to the needs of your child? Can you give me an example?
- Is there anything that you think the teacher could be doing to make things better or easier for your child?

Siblings:

- How would you describe the experience of your other child/children as your child with cancer returned to school?
- Have you noticed your healthy child having any adjustment difficulties? Can you describe them for me?
- Were there any support services available to your healthy child throughout this process? Please describe them to me.
 - Do you think that they were effective? How so?
- How would you describe your healthy child's peer relationships?
- How do they compare to those of your child who has cancer?
- Are you aware of any academic troubles that your healthy child has experienced since your child's diagnosis? Can you give me an example?
- Are you aware of any problems your healthy child may have encountered with other children regarding his/her sibling?
- Is there anything that you think or suggest could or should be done to make this experience easier or better for your healthy child? Can you explain?

Appendix E: Childhood Cancer Survivor Interview Questions

General Questions:

- How did you feel about going to school after you learned that you had cancer?
 - Were you excited? Scared? Nervous?
 - What made you excited? Scared? Nervous?
 - What helped make you feel comfortable?
- How do you feel throughout the day at school?
- What do you do if you're not feeling well?
- Do you get to participate in all of the activities at school?
 - What do you miss? And how do you feel about it? Can you give me an example?
 - If you miss out on certain activities, what do you do during that time?

Cognitive/Academic Questions:

- Some people say that children who have cancer have trouble with their school later on. They might find it harder to learn certain subjects than it was before they had cancer. Do you find that some school things are harder now? Can you tell me what you have difficulty with?
- Do these difficulties make you feel differently about school?
- Are you at the same level as the other kids in your class? Do you ever get behind? Can you tell me about this?
- Do you ever worry about how well you do in school? Can you tell me about some of these worries?

Social Issues:

- Do you feel like you have a good group of supportive friends at school?
- Some kids with cancer say that they sometimes have problems with other kids at school. Have you ever had any problems with any other kids? Can you tell me about them?
- Can you tell me about your friends?
 - Are they the same friends that you had before you got sick?
 - What kinds of things do you do or talk about with your friends?
- How and where do you hang out with or talk to your friends?
 - At recess or lunch?
 - Before or after school?
 - Weekends? Get together?
 - Phone or internet?
- Can you tell me about anything that the other kids at school have done to help you out or make you feel special? Why do you think they did that?
- Do you think that the kids at school know about cancer, or do you think that maybe they have it a little bit mixed up? Why do you think that?
- Do they ask you a lot of questions about being sick? If yes, what are some examples of questions that they ask you?

- What else do you think kids at school should know about other kids who have cancer?

Support Issues:

- Can you tell me about any programs or help that you had when you went back to school? Did anyone talk to your class?
 - What did you like best about the program?
 - Is there anything about the program that you think could have made things any better or easier for you?
- How do you feel about your teacher/s?
 - Are they helpful? Can you give me an example?
 - Supportive? Can you give me an example?
 - Sensitive? Can you give me an example?
- What are things that your teacher can do to make being at school easier or better?
- Has your teacher done anything to make things easier or better for you?
- Did you get any help from tutors, hospital teachers, or any special help at school?
 - What do you think about this help?
- What advice would you give to other children your age returning to school after being diagnosed?
- Is there something you wished you knew before going back to school?

Appendix F: Sibling Interview Questions

*This was approved by the Research Ethics Board but was not used in the study as a result of there being no siblings available to participate.

- Before your brother/sister went back to school, how did you feel about their return?
- In your opinion, how does your brother/sisters illness affect you?
- Has anything changed for you at school now that your brother/sister is back at school? Can you explain or give me an example?
- Do you think that you get treated differently than you did before your brother or sister became sick? Can you give me an example?
- When your sibling was away from school, did the other kids ask you a lot of questions? Can you give me some examples?
- Do you think that you have a good group of supportive friends at school? What makes you feel this way?
- What kinds of things do you do with your friends?
 - Are these things different than they were before your brother/sister became sick?
- Sometimes the brothers/sisters of kids with cancer get teased by other kids at school. Did you ever get teased by other kids at school because your brother/sister was sick?
 - Can you give me an example?
- Did anyone at school do anything that was especially nice for you? If yes, what?
- How did you feel when your brother/sister was back at school? Did this make things seem normal to you?
- Do you ever feel like you have to protect your brother/sister? Why or why not? Can you give me an example?
- Do you hang out with or play with your brother or sister at school? What sort of things do you do? Or, why do you not hang out with each other?
- Do you have the same friends as your brother/sister? Can you tell me about these friends?
- Did anyone come to talk to your class about your brother/sister's illness?
 - What kinds of things did they talk about?
 - Did you find this helpful? Why/why not?
- Is there anything that you can think of that someone could do or could have done to make things a little bit easier or better for you?

Appendix G: Child Assent Form

Dear (*Participant's Name*):

Your parents have allowed me to talk to you about a project that I am working on with my advisor at the university. The project is trying to understand your experiences and/or your sisters/brothers experiences of being in school after being diagnosed with cancer. I am going to spend a few minutes telling you about my project, and then I am going to ask you if you are interested in taking part in the project.

Who am I?

My name is **Marlene** and I am a student at Brock University. I work in the Department of **Child and Youth Studies**.

Why am I meeting with you?

I would like to tell you about a study that involves children/youth like yourself and I want to see if you would like to be in this study too.

Why am I doing this study?

I want to find out about your experiences of being in school after you were diagnosed with cancer and receiving treatment. I also want to know how your mom or dad, and brothers/sisters experienced your return to school.

What will happen to you if you are in the study?

If you decide to take part in this study I would like to spend about an hour or so talking to you about what it was like for you to go back to school after being sick, or while still being sick. I am interested in hearing your stories and how you experienced them. I will have a few questions to get the conversation started, but you can share anything that you think is important. There are no right or wrong answers; it is what you think that matters. If you do not feel comfortable answering one of the questions, that is okay. You do not have to answer any questions that you do not want to. If I ask any questions that you find hard or tricky, try your best to answer. If you have tried your best and do not know what to say, say 'I don't know' or 'I don't feel like talking about this'. If you have any questions for me, you can ask them too.

Could there be any problems for you if you take part?

I hope you will enjoy talking to me. A few people get upset or uncomfortable when talking about their feelings and experiences, and if they want to stop, I stop. I can call on their parents to help them, if they wish.

Will you have to answer all questions and do everything you are asked to do?

If I ask you questions that you do not want to answer, then tell me you do not want to answers those questions.

Who will know that you are in the study?

The things you say and any information I write about you will not have your name on it. I will change your name, so no one will know they are your answers or what you said about some of the things that we will talk about.

I will not let anyone other than my advisor see your answers or any other information about you. Your parents and/or brothers and sisters will never see the answers you gave or the information I wrote about you.

The only time I might have to break this promise is if I think you or someone else might be at risk of being hurt. If so, I will talk to you first about the best thing to do.

Do you have to be in the study?

You do not have to be in the study. No one will get angry or upset with you if you don't want to do this. Just tell us if you don't want to be in the study. And remember, if you decide to be in the study but later you change your mind, then you can tell me you do not want to be in the study anymore. You can also do this after you have already talked with me.

Do you have any questions?

You can ask questions at any time. You can ask now or you can ask later. You can talk to me or you can talk to someone else at any time during the study. Here is the telephone number and email address that you can reach me at: (905) 688-5550 ext. 5530 or marlene.oleiro@brocku.ca.

Thanks for all your help,
Marlene Oleiro

Youth Assent Form

Youth's name, printed: _____

Do you want to participate in this study?

_____ Yes

_____ No

Youth Signature: _____

Date: _____

Signature of the Researcher: _____

Date: _____

Appendix H: Sibling Assent Form

*This was approved by the Research Ethics Board but was not used in the study as a result of there being no siblings available to participate.

Dear (*Participant's Name*):

Your parents have allowed me to talk to you about a project that I am working on with my advisor at the university. The project is trying to understand your experiences of your brother/sister being in school after being diagnosed with cancer. I am going to spend a few minutes telling you about my project, and then I am going to ask you if you are interested in taking part in the project.

Who am I?

My name is *Marlene* and I am a student at Brock University. I work in the Department of *Child and Youth Studies*.

Why am I meeting with you?

I would like to tell you about a study that involves children/youth like yourself and I want to see if you would like to be in this study too.

Why am I doing this study?

I want to find out how you experienced your brother/sister being in school after he/she was diagnosed with cancer and receiving treatment. I also want to know how your mom or dad, and brother/sister experienced the return to school.

What will happen to you if you are in the study?

If you decide to take part in this study I would like to spend about an hour or so talking to you about what it was like for you when your brother/sister went back to school after being sick, or while still being sick. I am interested in hearing your stories and how you experienced them. I will have a few questions to get the conversation started, but you can share anything that you think is important. There are no right or wrong answers; it is what you think that matters. If you do not feel comfortable answering one of the questions, that is okay. You do not have to answer any questions that you do not want to. If I ask any questions that you find hard or tricky, try your best to answer. If you have tried your best and do not know what to say, say 'I don't know' or 'I don't feel like talking about this'. If you have any questions for me, you can ask them too.

Could there be any problems for you if you take part?

I hope you will enjoy talking to me. A few people get upset or uncomfortable when talking about their feelings and experiences, and if they want to stop, I stop. I can call on their parents to help them, if they wish.

Will you have to answer all questions and do everything you are asked to do?

If I ask you questions that you do not want to answer, then tell me you do not want to answers those questions.

Who will know that you are in the study?

The things you say and any information I write about you will not have your name on it. I will change your name, so no one will know they are your answers or what you said about some of the things that we will talk about.

I will not let anyone other than my advisor see your answers or any other information about you. Your parents and/or brothers or sisters will never see the answers you gave or the information I wrote about you.

The only time I might have to break this promise is if I think you or someone else might be at risk of being hurt. If so, I will talk to you first about the best thing to do.

Do you have to be in the study?

You do not have to be in the study. No one will get angry or upset with you if you don't want to do this. Just tell us if you don't want to be in the study. And remember, if you decide to be in the study but later you change your mind, then you can tell me you do not want to be in the study anymore. You can also do this after you have already talked with me.

Do you have any questions?

You can ask questions at any time. You can ask now or you can ask later. You can talk to me or you can talk to someone else at any time during the study. Here is the telephone number and email address that you can reach me at: (905) 688-5550 ext. 5530 or marlene.oleiro@brocku.ca.

Thanks for all your help,
Marlene Oleiro

Youth Assent Form

Youth's name, printed: _____

Do you want to participate in this study?

_____ Yes _____ No

Youth Signature: _____

Date: _____

Signature of the Researcher: _____

Date: _____

Appendix I: Demographic Questionnaire

*This was approved by the Research Ethics Board but was not used in the study.

Please complete the following form which asks questions relating to your child's illness and school history. The information provided will help to better understand differences between your family's experiences throughout the school re-entry process and the experiences of other families.

While this form does ask for personal information, rest assured that any information that identifies you or your child/children will not be included in the results of this study.

Please provide the following information regarding your child:

Name: _____

Gender: _____

Age: _____

School grade at the time of diagnosis: _____

Diagnosis: _____

Number of siblings: _____

Briefly describe your child's attendance history. For example, did he/she miss months of school, an entire year/term, weeks, or a few days here and there.
